

Witness Name: Michele CLAIRE

Statement No.: WITN0108001

Exhibits: **WITN0108002 - 04**

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MICHELE CLAIRE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 04 November 2018.

I, Michele Claire, will say as follows: -

Section 1. Introduction

1. My name is Michele Claire. My date of birth and address are known to the Inquiry. I am a sufferer of Hepatitis C and I am at stage 6 liver disease. I live with my partner in a property that he owns. I have lived here for just under one year, having previously lost two mortgages as a result of the infection. I have two daughters and two sons, all of whom now live away from home.
2. I intend to speak about my infection with Hepatitis C, possibly contracted through two blood transfusions, one, following the birth of my daughter in 1985, or a transfusion following the birth of my son in 1988. I may have been infected on just one of these occasions, or possibly both. In particular I will speak about the physical and emotional effects this has had on, my family and my career. I will also detail the treatments that I received after eventual diagnosis, and how all of the events before, during and after that infection have affected my life until today.

Section 2. How Affected

3. I have only ever received two blood transfusions in my life. I have no tattoos, no piercings apart from my ears, and I have never practiced promiscuous sex. I was diagnosed with Hepatitis C and believe that the only explanation for this has to come from one of the two transfusions that are detailed below.
4. On the GRO-C 1985 I was taken to Warneford Hospital, in Leamington Spa, Tatchbrook Road, (which has since been demolished), to give birth to my daughter. Up until that point, and during the birth, the pregnancy had been normal and natural.
5. Following the pregnancy, whilst in recovery, a junior doctor, who I had never seen before and who I did not see again, told me that he was going to give me a blood transfusion, in his words "you look a little peaky my dear". I was supposedly given this transfusion as my iron count was low, however my medical records show that I have had a low iron count since childhood.
6. It was clear to me that he was adamant I receive a transfusion. My ex-husband, who was present during the birth, took the side of the junior doctor, as he implicitly trusted the medical profession. I was not given any other information or advice at this point, and was I was hazy too, as this was immediately after the birth. I felt as though I was bullied into accepting the transfusion. I do not like anything invasive, and short of fighting them off, I could not object.
7. I know I was given the transfusion because I was connected to a blood bag via tubes that went into my arm. This lasted for around 2 hours, after which I was disconnected, but I had to remain in the hospital. In the following 3 days various blood tests were carried out on me, and I eventually discharged myself after 3 days.
8. The circumstances of my second transfusion began on the GRO-C 1988. I was on a flight to Tenerife and at the time was 6 months pregnant. I went into labour on the plane and the plane had to divert to

Manchester Airport. I was rushed to Wythenshawe Hospital and straight into surgery, where I was informed they were going to try and give me an epidural. I went under and don't remember much more, but was told afterwards that I was given an emergency caesarean and blood transfusion.

9. I remained in the hospital for the next 4 weeks while both myself and my son were in recovery. After receiving the blood during the birth, (blood that I had not given consent to receive), I refused 2 or 3 more attempts by the staff to administer further transfused blood whilst I was in recovery. At some point the surgeon came to speak to me to explain what had happened, and that they had given me the transfusion. He told me that it was not necessary to protect my life but the transfusion was in my best interest. I arrived at the hospital alone, so no one else could have given informed consent. The ward sister asked me repeatedly if there was anyone else I wanted to contact.
10. At no point during either birth was I informed of the risks from receiving infected blood through blood transfusion.
11. I have since tried to obtain my medical records from the Warneford Hospital, who, after its demolition, should have sent their records to the Warwickshire NHS Trust. I also tried to obtain them from Wythenshawe. On both attempts I have been unsuccessful.
12. From 1990 I was aware that something was wrong, and on various occasions went to my local GP with a number of different issues, generally feeling tired and run down .
13. In May 1999, as I was so unhappy with the progress being made and that I could not get the answers I needed, I went privately to see Dr. [GRO-D] [GRO-D] in York, and he carried out some tests, including an alanine aminotransferase (ALT) test.
14. The results of the tests indicated liver damage. In a letter, from Dr [GRO-D] dated 5th of July 1999, to my then GP Dr [GRO-D] at [GRO-D] Dr. [GRO-D] accused me of lying saying that I was "providing only a modest account of my alcohol intake", and also indicating that *results suggested I could be infected with Hepatitis C*. I

later obtained a copy of this letter from my medical records. I have sent a copy of it to the inquiry and it is exhibit **(WITN0108002)**,

15. I continued to suffer from worsening symptoms without a sufficient explanation as to what was wrong with me.
16. I was so frustrated and angry that finally, on the 1st of January 2003 I went to the **GRO-D** Group Practice in **GRO-D** to demand answers to the questions I had about my health. I kicked up a fuss with my doctor then, proceeded to the reception where I had a temper tantrum until a senior doctor came and agreed to take a set of blood tests, which he did.
17. I phoned the surgery 2 days after the tests were taken to find out the results, only to be told that they were not available and a doctor would contact me if it was important.
18. I was unhappy with waiting, desperate to know the results and certain that they would be available I decided to take matters into my own hands, again. I decided to obtain the results by other means. I phoned the Pathology Laboratory of the Haematology Department in York. Pretending to be Dr **GRO-D**, I asked for my results. These were given to me over the phone and confirmed that I had been infected with Hepatitis C.
19. I have a document showing test results, obtained from my medical records and dated 2/1/2003, with the final report on 3/1/2003 confirming that the results were known, before I was told by the surgery that they were unavailable. I have sent a copy of this report to the inquiry and it is exhibit **(WITN0108003)**.
20. 3 to 4 days after obtaining the test results I was contacted over the phone by Dr. **GRO-D**, he informed me that I was infected with the Hepatitis C virus. I asked if it was terminal and he responded that it can be, and that he was referring me to a specialist.
21. Dr **GRO-D** wrote to Dr. Charles Milson, a consultant and liver specialist at the York NHS Trust, on the 14th of January 2003, informing him of my infection and referring me for treatment.
22. At this point in my life I was working during the week in London, and returning to Yorkshire at the weekends. Dr. Milson referred me to Dr.

Mark Thursz at St Mary's Hospital in Paddington to be treated whilst I was in London.

23. I was extremely dissatisfied with the information I was receiving from my local surgery in GRO-D and when I was receiving it. The first medical professionals to be fully honest with me about my infection were Dr Millson and Dr Thursz. These doctors provided me with all of the information I needed to help manage the disease. My only criticism of Dr Millson and Dr Thursz is, that they had to have known about the contaminated blood problem that had come to light. The same contaminated blood that resulted in my infection. But they never volunteered to discuss that aspect with me, however I did discuss the subject with Charles Milson at a later date.
24. With Dr. Millson and Dr Thursz, I discussed liver progression, biopsies, the chances of getting a liver transplant, liver cancer, how the disease progresses, how the medication works against the virus, the chances of it being successful, the side effects of the treatment and how toxic the Interferon/Ribavirin treatment is. We also discussed how to best manage the disease and the treatment, not using toothbrushes and other dental care, and the risks of sexual intercourse. Mark Thursz added that he didn't consider sex to be very high risk.
25. I truly feel that I should have been provided with all of this information when I was first diagnosed with the Hepatitis C virus, in 1999. I consider the information provided by the consultants to be adequate, but information from GPs was diabolical.

Section 3. Other Infections

26. As far as I am aware I have not been infected with any other disease, and will not submit my body for an autopsy to check for CJD.

Section 4. Consent

27. During my first pregnancy, in which I received a transfusion I believe that the junior doctor, in agreement with my ex husband had not given me

the choice to refuse a transfusion. As I was hazy, tired and not entirely conscious following the birth I believe that I was not in a position to give my full, informed consent.

28. During the second pregnancy, I was unconscious and therefore unable to give my consent. As I was alone there was no one else who could have stepped in to stop the transfusion from happening. At no point during either birth was I informed of the risks of a transfusion or receiving contaminated blood.
29. To the best of my knowledge all blood tests that were performed on me were consensual.
30. As far as I am aware I was not used for the purposes of any research, although I cannot say for sure.

Section 5. Impact

31. Before diagnosis with Hepatitis C I began to experience a number of symptoms that I can now relate back to the disease. I suffered bad bruising from small knocks, extreme tiredness, my brain function would slow down making it very difficult to perform my work duties and I experienced terrible bouts of brain fog. There were times in which I knew I could perform a task at work, but was unable to do it.
32. These symptoms really started being noticeable around 1996 and got progressively worse. For my job I often had to digest high volumes of information, and found that I was unable to process the information adequately and that I was losing the ability to think on my feet.
33. Given that my job was highly demanding I was under constant stress, which was made worse by the fact that I couldn't carry out even basic aspects of my work. For instance, during 1996 I would be responsible for the duty phone at my firm of solicitors, It became apparent that I couldn't properly perform the task, and because of that, I would be letting people down. This is a really stressful feeling. I had to take some time off work and ended up shifting my responsibilities to cope and began managing the firm, rather than dealing with cases on a one to one basis, as I previously had done and enjoyed.

34. As a result of Hepatitis C I contracted cirrhosis of the liver, which I was first told about in 2004 after a biopsy at St Mary's Hospital in Paddington, when I was declared stage 3. On subsequent checks I was told that my liver had deteriorated; in 2005 an ultrasound scan at Princess Grace Hospital in Marleybone, W1U 5NY, showed I was stage 4/5, and a further biopsy in Yorkshire in 2006 showed I was stage 6.
35. Whilst the symptoms of Hepatitis C were bad and severely affected my ability to work, they were nothing compared to the effects that the Interferon/Ribavirin treatment has had on my physical and mental health, my family, my work and my social life. I was in extreme agony for the 4 years that I took the treatment.
36. I was originally told that if all went well I would only need one treatment lasting 6 months. This did not happen, I received 4 rounds of treatments, and in every case they were extended from 6 to 12 months.
37. During the first round, which I received in late 2003/early 2004 under the guidance of Dr Thursz in Paddington, I was still working full time. I took the Interferon/Ribavirin on Saturday morning at 9am so that the worst effects would be over earlier in the week, allowing me to work as much as I could. I was also required to go in and have blood tests taken three times a week.
38. Within 30 minutes of taking the medication, the effects of it would hit me and I could not function at all. I was unable to eat or move, my muscles ached, I had hot and cold sweats and I could not see or here properly. The symptoms were like full-blown flu.
39. These effects would last until Tuesday, by Wednesday they would fade and by Thursday and Friday I was able to function almost normally. On Saturday this cycle would start again and this was what I had to deal with for 4 years of my life. I completed all 4 rounds of treatment and 9 months into the 4th round my viral load was undetectable, however I was asked to complete the remaining 3 months of the treatment, which I did. The Hepatitis C has since come back but I have refused further treatment.
40. I suffered several other physical effects as a result of the treatment: terrible nosebleeds, severe hair loss and psoriasis. I still suffer from

psoriasis today, but I am unable to receive light therapy or injections to combat it, due to the weakness of my liver. The only thing I can take is Dovobet, a steroid cream. My immune system is considerably weaker than it used to be, making me much more susceptible to non-serious illnesses and infections, and making me very paranoid about even small health risks.

41. This paranoia meant that I was afraid to travel to London alone. When I needed to go to work and access the treatment, my partner would have to drive me all the way from Yorkshire. One occasion stands out in my mind. My son brought friends round, one of who had a cold. I lost my temper and screamed at him. This was the effect that this infection and its treatment were causing.
42. I also developed a phobia of needles, and sometimes had to ask other people to inject the treatment for me. On one occasion I had to ask my 11-year-old son to inject me.
43. As a result of my experience and the failure of the treatment I now have a deep distrust of the NHS and healthcare in general, and have had to turn to alternative remedies from China.
44. The frequent liver biopsies that I had to receive were extremely painful and crippling. For the procedure in London I had to lie on my side and a bolt was shot through my ribs and into my liver. I would then have to lie on my side, in pain for the next 5-6 hours in recovery. In Leeds the process differed in that the bolt was pushed underneath my rib cage. I would be in pain for 2-3 weeks after biopsies.
45. I did not face any difficulties in accessing the treatments, and Dr Millson and Thursz would always keep me notified of any medical developments in possible future treatment. As far as I was aware this was the best treatment available to me at the time.
46. The main obstacle I faced was that I had to pay for my own treatments whilst I was in London. I could not get it paid for whilst on the NHS, because I was away from my local NHS area. I got round this by paying for my treatments privately in London. I had been told that I would be reimbursed for this expenditure. But of course I never was.

47. Following my diagnosis in 2003 I was told by my GP that I had to inform all medical professionals whom I was in contact with about my infection with Hepatitis C. On telling my dentist at Bridge Street Dental Practice I felt I was treated like the scum of the earth. My dentist looked horrified, asked if I had seen my doctor for 'dependencies', implying I was a functioning addict, and he put on extra layers of protection. I did not return to any dentist for 5 years and am currently unregistered with any dentist.
48. Whilst going through some medical procedure in 2012 at St James's Hospital in Leeds, a junior doctor asked me if there were any veins left on my body that he could inject into, assuming that he was dealing with a drug addict.
49. In every hospital I can recall, when my blood was taken as a person infected with Hepatitis C, my blood bag would be placed within another bag with the image of a 'skull and crossbones' on it. On another occasion a phlebotomist refused to take my blood during a hospital visit, stating that she had to fetch a 'more senior person' I ended up taking the blood myself, handed it to her and then leaving.
50. The mental toll on my children and family was huge. Having previously enjoyed a comfortable lifestyle, my children had to adapt to my loss of earnings and savings, being forced to adopt a much more stressful and frugal existence.
51. During the treatment my children had to get themselves ready for school and deal with other household chores, I was unable to take them on family holidays, or even extended trips away. They were growing up and I was unable to have a normal family life with them because of the physical and financial impact caused by my having been infected with contaminated blood.
52. Prior to the infection when my finances were healthy we lived in the biggest house in the village and enjoyed a very comfortable and happy lifestyle. As more people in the local area found out about my infection their treatment of my family and me changed dramatically. We often received letters through the door with things such as 'we don't want your

type round here'. I would pass neighbours who now would not even look me in the eye.

53. I believe I have infected my partner with Hepatitis C, however he refuses to be tested.
54. As it was a small village my prescriptions would be delivered to the local post office. The shopkeeper noticed that I was being prescribed Ribovirin and must have looked up information on the drug. When he found out that it was for the treatment of Hepatitis C he told other members of the village and started rumours circulating. These rumours involved me being a drug addict and even, a drug dealer.
55. Because of this stigma my children could not stand to live in the area and moved away, I have not spoken to any of the local people since 2006, and choose not to travel into town for any reason, meaning I have to drive 5 miles to the nearest post office.
56. In terms of my education I do not believe I have suffered as a result of the infection.
57. The infection did however have a colossal effect on my work life, my ability to do my job and as a result, my income.
58. Just before my diagnosis I had made the decision to move to being self-employed for a much higher income, which formed part of my life plan to make enough money to put all of my children through school and university, save a healthy amount and move south to pursue other endeavours.
59. Despite trying my best to manage my workload and duties, after the first round of treatment I had to considerably reduce my time working, moving from 'managing' the law firm, to law cost drafting. During the second round of treatment I could no longer continue law cost drafting and had to further decrease my workload, and by the third round I could no longer work at all.
60. The financial problems my family and I have faced as a result of my infection with Hepatitis C have been some of the most long lasting and hardest to bear.
61. Before the financial effects of the infection began to be felt, my life was very stable financially. After making the decision to go self-employed I

had a regular income of £25,000 a month, I owned 3 properties across the UK, had 2 cars, went on regular holidays, ensured my children had everything they needed and felt like I was well on the way to achieving my life goals.

62. 1998 was the year when I feel like I had everything I needed and had reached the pinnacle of my professional life. I had private health and dental care, pensions and plenty of savings. Given my income and lifestyle I had around £30,000 on credit cards and monthly outgoings of close to £8,000.
63. As mentioned above I opted to pay for private consultation and treatment as the wait times would have been too great, and going on what I had been told there was only supposed to be one round of treatment lasting 6 months. Had I known that the disease would decimate my life I would have made other plans, such as stopping unnecessary expenditure or being more careful with saving.
64. That first round of treatment had been costing me about £1800 a month , just for the interferon and Ribavirin, let alone the payments for the biopsies which was in the thousands.
65. By the end of the first round of treatment I had only worked 3 months but still maintained outgoings of £8,000. By the beginning of the third round I was not working at all as I had decided to prioritise my health over my career.
66. The mortgage company we were with, for the family house, sold our mortgage to another company called Redhouse, tying our mortgage to the LIBOR rate and increasing our mortgage by £1,500 per month. I had no savings left and could not afford the mortgages, and as a result the family home was repossessed and I was taken to court by the mortgage company. I lost, and the judge, District Judge Handley, ordered me to pay the £25,000 I had just received as my first Skipton Fund payment, direct to Redhouse. The judge kept a suspended possession order on the house and we continued to live there and had to keep making mortgage payments despite no savings and a very small income through odd bits of work I was able to do, but I was conscious of the mistakes I was making.

67. I started my third round of treatments a couple of months later. This was 2008 and coincided with the national financial crisis, making it much more difficult to sell any of the properties. My diagnosis of stage 6 cirrhosis of the liver allowed the Skipton Fund to release a second payment of £50,000, of which judge Handley ordered £25,000 to be paid to Redhouse. I did not receive the money in time to make the payment, resulting in the mortgage company repossessing the house. I appealed the decision of DDJ Handley to the higher court in Leeds and lost.
68. When the house was eventually sold on 18 months had gone by, during which I was forced to continue to pay fees and interest, leaving me with no equity. If the house had been sold in time I estimate that I would have received £700,000 from the sale of the house.
69. We moved to the smaller house I owned just before the fourth round of treatment started. This house was then repossessed as I could not make the mortgage payments and we moved into rented accommodation. All I had left as an asset was a small amount of equipment that had been stored in this house. After the final round of treatment came to an end and my viral load showed me to be clear of Hepatitis C, I took this opportunity to assess what I needed to do to survive financially.
70. At this point I was living off a £4,500 quarterly payment from the Skipton Fund. I still owned a flat in London, but my daughter had taken over paying the mortgage as I was unable to. I estimate my total loss of assets as a result of infection, not including loss of income, to be £1.7 million. My loss of income I calculate to be £4.2 million, given that I was on a day rate of £1,500, I usually worked 6 days and this should have continued over 14 years. This lost income and the thought of what I could have had, makes me feel sick and is highly distressing. The infection has forced me to live in my partner's dead wives house and I hate it here.

Section 6. Treatment/Care/Support

71. At no point was I offered any counselling or psychological support, nor would I have accepted any as I do not believe in depression. In place of depression all I felt was a deep anger towards the NHS, and the

infection itself. I am aware of the support that is available as I have read it on the website.

Section 7. Financial Assistance

72. I did not find out about any of the funds and trusts until 2008, when a lady working in the benefit centre, where I had gone to seek any assistance I could find, informed me of the Skipton Fund.
73. I cannot at any stage remember being told about any pre conditions for eligibility when applying, however due to the treatment I was, at that time, not fully aware of everything that was going on in my life, and may not have understood.
74. In order to receive the £25,000 initial payment from the Skipton Fund I had to fill out a form, which was sent to me following a phone call to Nick Fish, the Fund administrator at that time. This then had to be corroborated by doctors and consultants and sent to the Skipton Fund. The whole process took about 3 months.
75. The second Skipton payment of £50,000 was released following corroboration by my consultants that I was at stage 6 cirrhosis of the liver, and was completed much faster than the first.
76. I received quarterly payments from Skipton initially of just over £3,000, which later rose to £4,500, and this payment was later taken over by the England Infected Blood Support Scheme (EIBSS). I also had my winter fuel allowance covered by Skipton, however I had to apply to the fund for that.
77. I applied for long-term sickness benefit, but this was denied to me as I was too sick to attend the meeting.
78. I think the Skipton informed me of the Caxton Fund, but I have not received much support from them. After Skipton closed they took over the winter fuel payments, which I had to apply for via email. On one occasion they refused to pay as they 'lost' my application email.
79. I have spoken to them once since but the person I spoke to was very condescending, making me feel as though I was begging for money by

speaking to them, so as a result I have given up speaking to them (Caxton).

80. As yet I have received no support from the EIBSS. I sent an enquiry email on the 9th of April 2018, wanting to know what was available and what I was entitled to, to which they replied on the 28th of September 2018 !.
81. My only observation on the schemed and trusts available for support is that I have very low expectations and they always live up to them.

Section 8. Other Issues

82. I have been asked if there are any questions that I would like to put to the Inquiry team. I would like to ask the following:

Is there a possibility of me giving evidence against Dr GRO-D for what he did to me?

Why we cannot in this country sue the American pharmaceutical companies?

I wish to know if any part of government or any government controlled department or organisation or subsidiary, or any persons or organisations acting on behalf of or with approval from 'any' government department or organisation with knowledge of these issues has requested and or received any funds from Any American organisation involved with or concerned with or who has knowledge of the contaminated blood, either sold, given or distributed in any fashion to the UK either directly or via a third party. And if so, how much and what happened to it.

The above is on the basis that there must have been something put in place for an agreement, meaning that recipients of contaminated blood could not take action in the USA. There is not a minister alive or dead

who would not have got some financial mileage out of this, for Government coffers.

I would personally like to ask that question at the hearing and preferably to the Chancellor of the Exchequer.

If this Inquiry will cost £10 million, why not divide it up amongst the infected? Some people need cash now.

83. I would also like to add that in early 2010 I was contacted on the phone, by a junior doctor, Dr [GRO-D], at the [GRO-D] practice who wanted to tell me that there had been a meeting in which they discussed removing the parts of my records that referred to my being infected. Dr [GRO-D] told me that Dr [GRO-D] had said, to leave them in but “jumble them up” and intimated that I would not be clever enough to match the records up.
84. On 17 March 2010 I wrote a letter of complaint to the [GRO-D] Group practice, the complaint was dealt with by Dr [GRO-D]. In his reply to me (under my proper name, that is known to the inquiry) dated 20 April 2010, he lays out a chronology of events in relation to my concerns. He details communications between Dr [GRO-D] and himself relating to consultations I had with Dr [GRO-D] and his observations relayed back to Dr [GRO-D] my then General Practitioner.
85. Dr [GRO-D] mentions that there were consultations between myself and Dr [GRO-D] in May 1999 and June 1999. He then states, that in a letter dated 5 July 1999 (mentioned above WITN0108002) there was a handwritten comment suggesting that you (I) may have Hepatitis C and that blood was at the reference laboratory for confirmation. Is this a testing without my knowledge or consent. They certainly never told me what was happening.
86. Dr [GRO-D] goes on to say that Dr [GRO-D] had stated he would be reviewing me again and that there was no further correspondence.

87. There is then, an apology on behalf of the practice that I was not followed up on this issue until 2003. I have kept a copy of this letter and handed it to the inquiry, It is exhibit **(WITN0108004)**
88. Dr **GRO-D** and Dr **GRO-D** had met on the 30th March 2010, they explained that what had gone on before with Dr **GRO-D** was a 'provisional result' and that the practice were under the impression that I would be seen again by Dr **GRO-D**. As a definite diagnosis had not been made at the time the result wasn't noted on my records in any other way.
89. Shortly after this meeting I received a letter from Dr **GRO-D** stating that they were putting practices in place to ensure 'That this does happen again'. Presumably, a typing error, unbelievable !.
90. I feel so strongly about this whole issue that I have no requests regarding anonymity. I would very much like to give my evidence orally. I have been told that I can change my stance regarding any anonymity issues, at any time.

Statement of Truth

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

Signed _____ **GRO-C**

Dated 28 February 2019