

Witness Name: Carol Watson

Statement No.: WITN5750001

Exhibits: **WITN5750002-3**

Dated: 16.10.21

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF CAROL WATSON

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 July 2021.

I, Carol Watson, will say as follows: -

#### **Section 1. Introduction**

1. My name is Carol Watson. I was born on GRO-C 1960 and my address is known to the Inquiry. I was previously employed as a Customer Manager for an Insurance company but I had to be medically retired. I live in GRO-C with my husband Clark. I intend to discuss my infection with Hepatitis C (HCV) which I contracted from a blood transfusion during the birth of my first child in 1979.
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. My family has not been involved in any prior litigation.
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 will have the right to reply to that criticism.
5. I do not wish to be anonymous and I do not wish to provide oral evidence to the Inquiry.

## **Section 2. How Infected**

6. I was born and raised in GRO-C and I have lived there all my life. I have been married to my husband Clark for 43 years and we have two children; Barry who was born in 1979 and Stephanie who was born in 1988. Both of my children are now married and I have six grandchildren; five grandsons and one granddaughter.
7. On GRO-C 1979, when I was 18 years old, I gave birth to my first child, Barry. This was a forceps delivery as there was a delay in the second stage of my labour, and shortly after the birth, I haemorrhaged.
8. I had to undergo a dilation and curettage (D&C) procedure and I was transfused with four units of blood. I provide to the Inquiry, **Exhibit WITN5750002**, which supports this assertion. Exhibit from Dr Pepae, registrar to Dr Lynch and dated 12 March 1979. This letter details the transfusion and delivery.
9. I remember watching the blood, seeing it go in, whilst also hearing everyone whispering about my brand-new bouncing baby boy with his big brown eyes and brown hair.

10. I was kept in hospital for seven days. Clark was not allowed in to visit me or the baby for the first two days.
11. I cannot remember exactly what I was told about the blood transfusion as I was very young and had just had my first baby, so I would have been quite overwhelmed. However, I do not recall being given any information about it from doctors at the time or upon discharge from the hospital. I also do not remember appearing yellow or having any other symptoms of hepatitis C at that time.
12. Once we brought the baby home, we just got on with life as a family. We welcomed our second child, Stephanie, in 1988.
13. I was never contacted to say I might have been infected, life just continued as normal until I started to become ill in late 2008. Although I was not diagnosed with hepatitis C until 2020. I am sure it was manifesting itself far earlier than this, in particular, the way I was struck down with a series of infections that were not responsive to antibiotics and which became so serious they were life threatening. I will discuss these in further detail below. I exhibit to the Inquiry (**Exhibit WITN5750003**) a list of my current medications and summary of my active/past health issues from GRO-C 1979 to 8 Dec 2020 to assist with this statement.
14. Towards the end of 2008, I started to lose weight quite rapidly. Initially, I thought I might have thyroid problems so I went to the doctors and my thyroid was tested, but it came back clear. I lost about six stone in a short space of time; I went from dress size 22 to a size 10.
15. Once the tests on my thyroid came back clear, I started to worry that I had cancer, I became very concerned and anxious. I had lots of blood tests. Nothing was detected; no thyroid problems, and diabetes didn't show up at this time either. My mum had died that year, so the doctor assumed I was stressed and had lost weight as a result of that.

16. I went on to be very poorly. I became very lethargic and tired, and I started falling asleep all the time. I didn't want to go out anywhere. This continued into and throughout the next year.
17. On 1 November 2009, I fell over the dog's water bowl and landed on my backside. After I got up, I felt sore, but I thought I had just bruised it. Later, my lower back began to swell and the area remained painful.
18. I started to get some discharge from the bottom of my lower back, and so a couple of days later, I went to the drop-in centre at my local Minor Injuries Unit. I was advised that I had an abscess and was given paracetamol and antibiotics.
19. By 8 November 2009, my symptoms had gotten much worse. I had further discharge from the wound, and even more swelling. I was told it was a perianal abscess and so it was lanced, drained and packed. I was kept in for two nights before being discharged home. I was also given more antibiotics to treat the infection.
20. When I attended my GP to have the wound re-dressed, the practice nurse and one of my GPs, Dr Lotsu, were concerned that the infection was beginning to spread, and thought I may need intravenous (IV) antibiotics. I was then readmitted to Sunderland Royal Hospital.
21. At the hospital, I was told that I would require further drainage of the abscess and another surgical procedure further down my bottom. I was given IV antibiotics and monitored for a few days. I underwent surgery on 14 November and was discharged on 16 November. I was in even more pain by this point, and the pain seemed to be moving further down my leg.
22. Once I was home, I was having daily visits from the district nurse team. The district nurses raised concerns about the wound not healing and from the amount of exudate coming from it. My husband was having to change the

bed two or three times a day because of the amount of fluid coming out. There was also a strong smell coming from it.

23. On 20 November 2009, one of my GPs, Dr Crompton, came to see me at home and inspected the wound. Dr Crompton was fantastic. She called the hospital for further guidance as the exudate was very offensive and it smelt like faeces. There were also lumps around the area where I had originally fallen. Dr Crompton advised that I would need to go to hospital immediately for further review and sent for an ambulance.
24. I was stretchered out of my house and to the ambulance. I could not walk and I was in so much pain. I was taken to the Sunderland Royal Hospital and was seen by a consultant, Dr Small. I was asked if I was diabetic and a finger prick test was carried out, which showed my sugar level to be 26, which was high.
25. I was then sent for a CT scan which revealed gas and fluids. Dr Small advised that there was an infection tracking down my right leg and they would need to do more surgery urgently.
26. I called my husband who had gone home and told him to come straight back. I believe the doctors told my husband that I had Necrotising Fasciitis (NF). Dr Small advised that if I was not operated on immediately, I would only have twelve hours to live because of toxic shock. This was very scary and incredibly stressful.
27. I was taken down to the ICU at around midnight for the debridement of my bottom. The NF had eaten away at all of the fat in my bum. I had a number of drips in trying to counteract the toxic poison going around my body.
28. The following day, I underwent colostomy surgery and further debridement of my right lower limb wound. Following this, I was placed in the Intensive Care Unit (ICU) for four days, of which I have no memory.

29. Over the next few weeks, I had around eighteen separate operations involving debridement, removing dead skin and VAC dressings being replaced. I was essentially having operations every two days, and having the leg re-bandaged, but the infection was still moving further and further down.
30. I was also diagnosed with diabetes, which came as a shock as I had had several tests only a year before and every time it came back negative.
31. On 21 December 2009, I was told by Mr Mahawar, Consultant Plastic Surgeon, that my right leg would need to be amputated as they could not stop the spread of the infection. The first time I was told this, I was alone. The doctor who told me was quite blunt. I was in shock. The second time it was mentioned, the doctor came to my bed and had a nurse with him. My husband was also with me. He said "I'm afraid we are going to have to amputate it".
32. My husband spoke with Dr Small and asked if there was any way the leg could be saved as that's what I wanted. The orthopaedics team then pushed for further debridement on the calf in order to save my leg, which is what ended up happening. They carried on doing this until the leg was spotless, and fortunately this technique was eventually successful and it saved my leg.
33. Once the infection was under control, I received care from plastic surgeons and was referred to Mr Erdmann at University Hospital Durham. It was imperative that I was completely infection-free before any plastic surgery and I had to be built up beforehand. At this point, I only weighed 7 ½ stone. I was so thin you could see my bones and I had started to lose my hair. I remember having to take in around 1,800 calories a day so that I could put on weight before I was able to have the skin graft surgery.

34. I had to have the wound cleaned regularly which was very uncomfortable. I would be taken down and showered down with water, and I would often be screaming as the pain was so bad.
35. In early January 2010, in the middle of a snowstorm, I was transferred to Durham to undergo the skin graft procedure. The skin grafts were successful on the top area but not on the bottom. I was very anxious by this stage as I had been in hospital for several months.
36. By now, my mobility was very poor. It took me a very long time to get out of bed and I had to undergo lots of physiotherapy before I was able to move around again. I eventually started walking with the use of a zimmer frame.
37. I was finally discharged around Easter 2010. I had been in hospital for six months. Throughout my time in hospital, I had only let my husband come to visit me. I didn't want anyone else seeing me like that. For my return home, I was provided with a hospital bed and commode in the living room, and my husband slept near me on a z-bed. I had visits from district nurses every second day. They gave us the equipment we needed, but we were left a bit on our own.
38. I finally started to make a recovery at home, however I was left with an open wound that has to be dressed every second day. I have since been told this will never heal and there is nothing that can be done for it.
39. In Summer 2010, I developed a pyoderma gangrenosum. This is another issue which I am aware of, from my husband's research, is linked to hepatitis C. At one stage, I had treatment on the skin on my hands. This involved dead skin being removed from my hands and my hands being washed in some kind of liquid. I was kept in hospital for five days, and then my husband took me to Durham every other day until the nurses felt he was able to do the dressings himself. I was not allowed to do anything with my hands, which meant I was unable to change my stoma. Instead, I had to rely on my husband to do this for me, which I found very embarrassing.

40. My hands are still very painful whenever it gets cold, and my grip is not the same now as a result of the pyoderma gangrenosum.
41. In late 2010, I had another infection in my right leg which had spread into my calf muscle. I had to have yet another operation to remove the infected tissue. By this time my kneecap was destroyed by the various infections and I began to suffer from septic arthritis.
42. In July 2011, I underwent a similar procedure as the infection had returned again. I was given two options; knee fusion using a Wichita nail joining my whole leg together, or amputation from above the knee. A knee replacement was not possible due to too much bone having gone from my kneecap. I did not want to have my leg amputated so I opted for the fusion.
43. All was okay for around eighteen months until I knocked on my leg, which led to another infection. Antibiotics did not work. The infection was making its way towards the Wichita nail and so I had to go through yet more surgery to remove the nail. This involved cutting open and breaking my fused leg to remove the nail, before cutting one of my calf muscles and sewing it onto the front of my shin to cover the hole where the infection was; essentially a reconstruction of my leg. This was yet another extremely painful and distressing operation.
44. In May 2017, the shin of my right leg suffered another infection. I called my husband when he was on his way back to work. He has since told me that I was talking gibberish about black bags, and then the call cut out as he was on the train. When he arrived in Aberdeen for work, he kept trying to call me back but couldn't get hold of me. He called our neighbour who came to the house and she found me lying on the floor. I had slipped off the bed and onto the floor, opening my scar and exposing my shin bone. I was in so much pain and this injury then took two years to heal.



45. I have never had knee or any other joint problems prior to the NF. I have a lot of scar tissue all over my right leg and the injuries are very visible. I'm very conscious of this and it has a huge impact on my wellbeing. Furthermore, my right leg is now 28mm shorter than my left and I can only mobilise with crutches.
46. From 2017 to 2020, I toddled along. I continued to have smaller infections. I was still tired, lethargic and was vomiting regularly, particularly in the mornings after breakfast. However, I felt good in comparison to the previous several years.
47. In October 2020, one morning I suddenly went yellow, from top to bottom. My skin and eyes were completely yellow, and my pee was very dark. I was sick and had stomach pains.
48. It took a long time to get through to the GP. At my GP surgery it is very hard to get an appointment, and it has been even worse since the coronavirus pandemic. I finally spoke to a doctor, who said if it got any worse to call 111.
49. I was initially diagnosed with gallstones. They went in through my mouth to remove them. On my records, it states that I had my gallbladder removed, but actually I did not. It is strange that my records are incorrect and a little worrying.
50. On 20 November 2020, I was experiencing a lot of pain. I returned to my GP. I had severe diarrhoea and I couldn't stop it. At one point, I went to the toilet and I lost my memory. I didn't know who I was, where I was, who my husband was and I couldn't walk. As I mentioned previously, I have a stoma following the abscess and NF issue. The bag kept rapidly filling up with green poo and at one point the bag just flew off.
51. My husband felt helpless and called for an ambulance. My blood sugars were okay, but my blood pressure was high and my heart rate was low. I was taken into hospital and ended up being kept in for seventeen days.

52. My levels were spiking overnight and my stoma would not settle. I was being tested for everything but HCV. They carried out CT scans and all sorts of other tests, but they could not work out what was wrong.
53. I was by myself for seventeen days, panicking and alone. I could not have visitors because of the Covid restrictions. Then, seventeen days after I was admitted, the doctor pulled my husband aside and told him I had been tested for HIV and HCV. However, they had not told me. My husband told me that they had said I was tested for this as an absolute last resort.
54. I was not asked whether I had ever received a blood transfusion. I was then discharged from hospital. The results take around ten days after the test and so I had to just go home and wait.
55. Several days later, a doctor from the hospital called and told me over the phone that I had tested positive for hepatitis C. I was shocked and I started crying. I felt knocked out and you could have blown me down with a feather. My hepatitis C diagnosis is also detailed in **Exhibit WITN5750003**.
56. I have never done drugs, never drunk too much and never been promiscuous. I've been married since I left school.
57. The recurrent infections and the fact that the antibiotics did not work to clear them was because of the underlying hepatitis C infection. However, at that point myself and clinicians were totally unaware of it. Since undergoing the hepatitis C treatment, I have not had any issues with infections.

### **Section 3. Other Infections**

58. I was tested for HIV at the same time as the hepatitis C test. The HIV test returned as negative.

59. I have had countless infections over several years prior to finding out about the hepatitis C. A number of which became very serious and even life threatening, particularly the NF. I have no doubt that the underlying reason for me being so susceptible to infections, and the fact that they were so difficult to treat, was the hepatitis C.

#### **Section 4. Consent**

60. When I received the blood transfusion, I was 'out of it' from the procedures and so I don't know about consent. However, I know that I needed it to save my life, and so there would have been no question.

61. I was not told that I was being tested for HIV or hepatitis C beforehand, but this was mentioned to my husband.

#### **Section 5. Impact**

62. The many infections and operations I have had to endure as a result of my underlying hepatitis C infection have been both physically damaging and mentally traumatising.

63. I have also had to be reviewed by Ear Nose and Throat (ENT) specialists, due to the fact that I had been having problems with my voice. I was advised that the intubation during the multiple surgical procedures that I had been through had caused scarring to my larynx. I've had speech therapy because my voice was so weak, hoarse and breathy. Therefore, I find it difficult to have a conversation because who I am speaking with will have trouble hearing me.

64. I have since been diagnosed with diabetes and I believe that this diagnosis is a result of the HCV. I have read that HCV can result in diabetes type 2. There is no his history of diabetes in our family. I am insulin dependent and have to take it twice a day.

65. In the years following my blood transfusion, I suffered from a number of miscarriages. Detailed in **Exhibit WITN5750003** is a "missed abortion" which is an early pregnancy miscarriage. Through my research, we have become aware that miscarriages can happen as a result of HCV.
66. Before all of this happened, my husband and I were a very active couple. We enjoyed going for walks in the hills with the dogs. I used to be involved in lots of different activities. For example, I used to swim at least twice a week and I regularly went on long walks in excess of ten miles. I also used to enjoy bike riding and running. I am unable to do any of these things now. Now, I can't even walk on the beach.
67. I loved both the challenge and focus of work and also the social aspect of it, but because of all this I can no longer work. My employer tried to accommodate me in the office, however despite their best efforts, for safety reasons, it was simply not viable. I therefore ended up having to be medically retired.
68. I can't do the things I want to do anymore. I can't drive anymore because of my fused leg and open wounds and so I can't get out and about. I really miss driving and the independence it gave me. I never got to drive my brand-new car. I feel like I have lost a lot of my freedom. I have to do all of my shopping online now.
69. I rely on my husband for a lot and as he works offshore, he has had to take a lot of time off work to look after me when I have been unwell. When he is away working, my daughter helps me a lot and is like my carer. She also helps me a lot with jobs around the house like cleaning and ironing.
70. I used to have a very busy social life and I enjoyed going out with friends for meals and a drink, but this has all stopped. Mostly because of my stoma and my concern that it might leak. Furthermore, my husband stopped drinking in 2009, so that he can always be on hand if I need him. Although he was never a big drinker, socially, this has had an impact on him.

71. I can't play with my grandkids like I would want to as I can't get down on the ground to play with them. I have six wonderful grandchildren, and some are very young. I would love to play games and pick them up but I can no longer do this.
72. I can't fly or go abroad due to the wound. I can't get too much sunlight on my leg due to the wound. I can't even sit too long on my bum due to the wound. So many things are just too high a risk of infection for me, even something like getting on and off a boat is risky.
73. I can't walk far, only about 50 meters. This means I can't walk our dog; he is a German shepherd and is wonderful. I have to just let him run in the garden when my husband is away or rely on someone else to take him out.
74. I can't bend my leg so even something like sitting in a theatre is tricky. I'm restricted where I can go due to access and types of seats. For example, in the theatre, I would have to sit in an aisle seat. However, then people often knock on my leg, which is potentially extremely problematic.
75. We are not financially sound like we should be at this point. My husband has taken lots of time off work to look after me, and as a result, he has lost a lot of money.
76. The fact that the NF left me needing a stoma has also had a huge impact on my quality of life, and has meant I have stopped doing so many things I would otherwise have done.
77. The diagnosis of hepatitis C and the prior infections have had a significant impact on my mental health. I've had flashbacks of being in hospital and have suffered triggers from the smell of antiseptic, bringing back memories of my pain during my hospital stays and operations. I have at times had very low moods. My first grandson was born in 2009, and I have always been

very close to him. He has given me the strength and motivation to carry on. I believe if it wasn't for him, I would not be here now.

78. Most significantly of all, I have lost a lot of my confidence and independence. When I reflect on my life now compared to how it used to be, it is vastly different. I used to be very outgoing and up for a laugh. I was very sociable and enjoyed meeting and getting to know new people.
79. Since the diagnosis of hepatitis C, I have become even more withdrawn in myself. Hepatitis C has changed my life in so many ways, however none for the better. I am alive, just not the same person.
80. This whole ordeal has taken so much time out of our lives. I mostly have one appointment a week but I sometimes have two appointments a week. These appointments including HCV appointments and others which I believe are directly linked to the HCV (as discussed previously) have taken place over the last twelve years. Since 2009, I have attended well over one hundred hospital appointments and I have endured forty-eight operations.
81. My appointments are never-ending. I recently had a fibroscan of my liver in relation to the HCV, but I have been asked to go back for another fibroscan because the last scan was inconclusive.

## **Section 6. Treatment/Care/Support**

82. When I was first told about my diagnosis of hepatitis C, my husband asked the doctor if he and my daughter would need to be tested. The doctor hadn't mentioned it beforehand, but he replied "yes, you better have a test." This was extremely worrying for us all.
83. It was only later, during an appointment at Sunderland Hospital, that I was finally sat down and we were able to look at where the infection could have come from. My appointment was with Julie Walker, a specialist endoscopic nurse and she was brilliant. She asked me lots of questions, the last

question that she asked me was "have you ever had a blood transfusion?". This was the point at which we worked out that I had been given infected blood during the birth of my son.

84. Julie also mentioned the family being tested as a precaution. I was surprised that the doctor who I had spoken to beforehand had not said this to us.

85. The next time we saw Julie it was about treatment options. She also provided some advice regarding precautions, for example not to have unprotected sex. She said it was not likely to be transmitted that way, but it could be, and also said not to share toothbrushes etc.

86. I was offered a course of treatment called Epclusa (sofosbuvir/velvetasvir). I was advised that before I could commence the treatment, that due to costs, it would need to be passed by a Newcastle panel. I felt terrible to know this. I had never done anything wrong and I had contracted hepatitis C through no fault of my own. At this point, after everything I had been through, I felt like 'why me?'

87. I was led to believe that people who require the treatment as a result of acquiring hepatitis C through drug abuse, get it straight away, while I had to wait to be considered with the possibility of rejection. I was worried about what I would do if the panel said no to the treatment. I was aware the medication would cost £10,000. My husband said to me that we would buy it if necessary, but I didn't want it to have to come to that.

88. The treatment was then approved by the panel. I began the treatment at the end of January 2021. I had to take one tablet a day for twelve weeks.

89. I was told to look out for my blood sugar levels dropping, but mine actually went up. I was also told I might get headaches, feel sick or get diarrhoea. Fortunately, I didn't get any side effects, apart from my blood sugar going up. I have been through so much, that sometimes I get through difficult

things easily when other people struggle, as I have been through much worse.

90. My viral load was 1.3 million IU/mL at the start of treatment. Half way through my treatment, I had to go in for blood tests and my viral load had dropped down to 20 IU/mL.

91. I have recently had a blood test to determine if I have cleared the virus completely, and I am currently awaiting the results.

92. I feel that the treatment was explained clearly to me. We were told there would be other options if this treatment didn't work, but luckily it does seem to have worked.

93. No counselling has ever been offered to me regarding the hepatitis C. I have called the Hepatitis C Trust and they have provided practical support, however no counselling support.

94. I saw a clinical psychologist during my time in hospital with NF as I was experiencing very troubling visual disturbances and hallucinations. For example at one point, I was seeing spiders everywhere and I was very concerned about this. I was advised that this was down to the heavy medication that I was on, which included morphine.

95. In my experience, all of the doctors that I have seen throughout all of my health issues were at least fairly good, and some were excellent.

96. I do not feel that there were any obstacles regarding treatment or testing. The issue was that the infection was overlooked for such a long time, and I was only tested as an absolute last resort. My life may well have been a lot easier had I been tested and diagnosed earlier. Since completing the treatment for hepatitis C, I have not had any infections, which has made a huge difference to my life.



## **Section 7. Financial Assistance**

97. Julie, the specialist nurse at Sunderland Hospital, told us about the Skipton Fund. She helped me to fill in the forms and Dr Sinha, a consultant, signed them.

98. I received the Skipton Fund stage 1 straight away. This was in January 2021. My monthly payments started in June 2021. I have now received £50,000 as a lump sum, and will receive around £19,000 per year in monthly payments. There is also a heating allowance.

99. I am receiving Stage 2 of EIBSS. However, I am unsure what it is for because it has never been explained to me.

100. My hepatitis C infection was missed for many years despite me having numerous problems attributable to it. This means I have missed out on years of financial support which I would have been if clinicians had it been picked up on it sooner when my health issues first started. I therefore would like to receive a backdated payment and I have calculated that I have missed out on over £100,000 worth of monthly payments.

## **Section 8. Other Issues**

101. The fact that the case for my treatment had to be put to a decision-making panel was very distressing for me. I've worked and paid all my dues, I was infected with hepatitis C through no fault of my own, and I have suffered immensely as a result over the years. This was made even worse by the fact that I was told other patients who had been infected as a result of drug abuse had been given treatment much easier, including some patients who have had it on more than one occasion. Meanwhile I had to wait for approval; feeling like the decision could go either way. I was made

to wait while the merits of my case were assessed by people that I had never even met and this significantly added to an already incredibly stressful situation.

102. In my opinion, the Government needs to own up to what has happened. So many people have lost their parents, children or other relatives. Money isn't everything but it can help to make life more comfortable for people who have already suffered greatly.

**Table of Exhibits:**

| <b>Date</b>                        | <b>Description</b>  | <b>Exhibit</b>     |
|------------------------------------|---|--------------------|
| 12 March 1979                      | Letter to Dr Lynch from Dr Pepae, Registrar, re: Carol Watson's child birth. Detailing forceps delivery and four pints of blood transfused. | <b>WITN5750002</b> |
| <b>GRO-C</b> 1979<br>to 8 Dec 2020 | List of medication and summary of significant active and past health problems. Detailing Carol's hepatitis C diagnosis and miscarriage.     | <b>WITN5750003</b> |

**Statement of Truth**

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

Signed                      **GRO-C**                     

Dated 16.10.21