Witness Name: Debra Caveney
Statement No.: WITN4679001
Exhibits: None
Dated: February 2021

# INFECTED BLOOD INQUIRY

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# WRITTEN STATEMENT OF DEBRA CAVENEY

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 September 2020.

I, Debra Caveney, will say as follows: -

## Section 1. Introduction

1. My name is Debra Caveney. My date of birth is GRO-C 1973 and I reside in Leeds West Yorkshire. I am married and a mother to 6 children, 5 girls and a boy. I am also a grandmother to 7 children. I intend to speak about my infection with Hepatitis C (HCV). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life and the lives of my loved ones.

## Section 2. How Infected

2. In GRO-C 1991 when I was 17 years old, I gave birth to my eldest daughter Rebecca. This had been a complicated pregnancy as I

had suffered from swelling, protein in my water and high blood pressure. I also had the stress of GRO-C to contend with alongside these health complications. As a result of this, it was decided that it was in my best interest and in Rebecca's best interest to induce me. I was taken to the St James's Hospital in Leeds to be induced early and my daughter was born a month before her due date.

3. In order to induce Rebecca's birth, I was put on a drip. It worked quickly and Rebecca was born just six hours later. GRO-C GRO-C. I was young and scared with GRO-C waiting outside, but at least my mum was with me, which gave me comfort. I didn't really question what the doctors and nurses were doing and trusted them with my care and Rebecca's care. I was never brought up to question my elders or superiors and I didn't feel like I could question these medical professionals either. I remember being very overwhelmed and exhausted following the birth.

4. I started haemorrhaging shortly after the birth and I remember being held up in the shower by a nurse while haemorrhaging, as I was too exhausted to stand up unaided. I was given a drip for about a day and some injections but I cannot recall being told what they were. Now I know that I was given fresh frozen plasma (FFP) during this period. I have no memory of being told that I was being given plasma or having my treatment explained to me at all.

5. I also remember I had very low iron levels following the birth and the photos of me in the hospital made me look so white I was ghostly. I was in hospital for about a week before being sent home. I gave birth to 5 more children in the years 1995, 1996, 1997, 2001 and 2004.

6. In 2000, I got very unwell with a fever and had pain and itching in my foot. The next day I couldn't bear weight on the foot and I went into hospital where I was told I had an abscess. I had it removed surgically

and I needed the dressings changed daily, which was done by a district nurse who came home. The wound took so long to heal which the nurse did not understand. Now looking back, I think this could be as a result of the HCV infection.

**7.** I believe sometime after this, I started catching numerous infections. I felt like I would catch anything that was going around and had to take antibiotics quite often. I also struggled with itchy skin around my stomach and legs and had to be prescribed a special aqueous cream with menthol in order to keep this under control. This issue continued for a long time and I am now aware these are symptoms of HCV.

**8.** I also had some red spots on my chest for years which I thought were like freckles. Only much later, my liver specialist said they were spider veins and linked to HCV. I also had aches and pains over the years but I put this down to being overweight, having lots of children to look after and a busy lifestyle.

**9.** In November 2003, around the time when my grandfather died, I suffered a miscarriage. Following this, I had an internal examination where they found a cyst on my ovary and I was told I would get an appointment to see a doctor about this. I never received an appointment about the cyst and I fell pregnant with my youngest daughter GRO-C, not long after the miscarriage.

**10.** I was exhausted during this pregnancy. I was sleeping for around 18 hours a day and I had five kids to look after. My partner at the time, Darren, had to take time off work in order to help look after them.

**11.** When I told my GP about how I was feeling, his first concern seemed to be that I wasn't looking after my children properly as I was sleeping so much. I felt he was more interested in judging me than listening to my issue and I had to explain that Darren was looking after the kids and I wasn't putting the kids in danger.

**12.** The GP reassured me by saying I was so tired because I was older during this pregnancy and overweight. I felt like he was just brushing me off and did not take me seriously.

**13.** While pregnant, I had a dream that my baby GRO-C was kicking me and saying that she was okay but something was wrong with me and I should keep getting checked. Following this dream, at 26 weeks pregnant I went to the hospital and saw a doctor as I was not feeling well.

**14.** I remember that the doctor I saw first at the hospital told me he was a trainee and not a consultant and asked if that was okay. I said it was fine and I explained to him about the tiredness and how unwell I was feeling. I was also suffering with some bleeding everyday which was very abnormal for me.

**15.** Later, a different doctor (a consultant this time) came to see me and took me in for a scan. He told me that Baby GRO-C was fine but asked me to come back to the hospital the following Monday to have my cervix checked in the colonoscopy department.

**16.** At the appointment on the following Monday, I was told they were going to take a biopsy of a growth they had seen on my cervix. I said to the doctor, 'I think I have cancer'. The Doctor told me to calm down and that nothing could be confirmed until they received the results. My mum also kept saying that I shouldn't say its cancer as I don't have the results yet.

**17.** A week later, I received the results confirming I had cancer. I was told the tumour was the size of a satsuma. I am sure this was linked to the cyst they had seen on my ovary less than a year before but I had never received an appointment about this.

**18.** My cancer notes have said that the tumour was 'slow growing' but I had a smear test just 18 months before my diagnosis and nothing had been picked up. That indicates it wasn't a slow growing tumour so I am not sure how they reached that conclusion. I believe that the pregnancy hormones were actually feeding the tumour and it grew very quickly.

**19.** Due to the cancer, it was decided that GRO-C should be born early. I was given an injection to help GRO-C's lungs strengthen. She was born by emergency C-section due to the size of the tumour and the risks a natural birth posed. Following her birth, I started to have chemotherapy, radiotherapy and brachytherapy in order to treat the cancer. I was under the care of Dr Cooper for my cancer treatment. I was given a blood transfusion in 2004 due to the chemotherapy treatment.

**20.** Although going through the treatment with a new-born was very difficult, I was very open about my treatment and had a lot of support. I had become part of the Charity, Jo's Trust and met lots of other people who had been or were going through what I had. This really helped me. I also had a community online that I could speak to if I had any concerns.

**21.** Being involved with the Jo's Trust was a great community and we did things like organise a petition to lower the age of cervical screening and went to Downing Street to hand it over. I was involved in organising various fundraisers and events. They also paid for me to fly to Ireland for a meeting where I shared my story, although I had no idea when agreeing to go that I was going to stand up and do that! Although I am less involved with the Trust now, it was a great tool in my cancer recovery.

**22.** Unfortunately, after I had finished my cancer treatment and had received the all clear, my health problems didn't go away. I started developing Lymphedema in my legs following the treatment and this made my mobility worse. I still struggle with this and getting treatment for the lymphedema has been a nightmare. The lymphedema department at St James's Hospital kept going on and on about my weight to the point where I told them their comments could make me suicidal. They often made me feel guilty by telling me that a bandage costs £7, even though I really need them. I hate visiting the clinic because of this.

**23.** At one point, a nurse at the Newton Surgery, who I didn't know, told me that my treatment had been halted for the lymphedema. She said that I needed to prove that I still had it and until I had an appointment with the specialist doctor, my prescription and bandages would be halted. Even though I explained to her that I badly needed the bandages to aid my mobility, she didn't listen and said I would be referred back to the doctor about my condition.

**24.** Due to having no treatment, my legs became so swollen they became infected and I had to go into hospital. When I finally had the appointment with the doctor, she was furious at the nurse who had cancelled my treatment; going without it for a couple of weeks had badly affected my condition.

**25.** I believe the lymphedema was linked to my cancer treatment but it could have been exacerbated by the HCV that I had not been diagnosed with at this stage.

**26.** In 2011/2012, when I was around 38 or 39, I decided to have weight loss surgery. I have always struggled with my weight and was about 35 stone at my heaviest. I had the operation at the BUPA hospital which is the Spire Leeds Hospital in Jackson Avenue, and I was under care of Dr Jeremy Hayden. I had a sleeve gastrectomy procedure done where they staple your stomach using titanium staples and reduce the size of your stomach. I had this specific procedure done as my bowel was not healthy enough following the cancer treatment to have a different type of weight lost surgery.

**27.** Unfortunately, this operation did not go as planned. My spleen had haemorrhaged in theatre. I believe my previous test results had shown some history of spleen issues and an increase in the size of my spleen, but this was never picked up.

**28.** I was extremely unwell following the surgery and they also diagnosed me with MRSA. I had had a MRSA test before hospital admission for the surgery and I was negative. I remember the doctor telling me that the hospital had 0 previous MRSA cases as they were very thorough with their cleanliness but three days after my surgery, I had caught it.

**29.** I also had two infections in my lungs and suffered a collapsed lung. I remember having to do lung exercises following this. I also remember having pain on my side when waking up from the operation. I was so unwell I thought I wouldn't make it.

**30.** About two weeks after the operation, I met Dr Hayden with my mother and sister for a follow up. He told me he had been worried about me after the surgery and had been monitoring me closely. He then went on to tell me that during the surgery he had realised that my liver had been damaged by cirrhosis and decided to take a biopsy; this explained the pain on my side. He told me that I had tested positive for HCV and that he believed I must have contracted it about twenty years ago, given the severity of my cirrhosis.

**31.** I remember Dr Hayden mentioned a couple of my small tattoos I have and questioned this being a cause of my HCV. However, I knew this was not the case. I remember having the first tattoo in around 1992, when my eldest daughter was around 18 months old, and being extremely nervous about the needles. Because of my nerves, the tattoo artist showed me that the needle and that the items she was using were sanitized and coming out of a fresh packet.

**32.** The tattoos were done at safe and legitimate studios and I know the tattoos did not give me HCV. Dr Hayden also asked me if I had been to some specific countries, which I had not.

33. I had no idea how I could have come to be infected and it was a very confusing time. I was also told that if the liver damage had not been discovered during the weight loss surgery, I would have died in about fifteen months and they would have put down my death as linked to obesity.

34. Looking back, it is shocking that liver damage to this extent was not discovered before as I had abnormal LFT results in previous blood tests; a HCV test should have been done far earlier. In addition, I do not understand why general health checks, including checking my liver, were not done after I had undergone cancer treatment. I was constantly in and out of hospital and had always assumed any additional health issues would have been picked during the many blood tests and investigations done.

35. After the weight loss surgery, I had lost 9 stone very rapidly but I was unable to eat and I had issues with my gallbladder. I was very weak and couldn't even get out of bed. I'm not sure if the condition of my liver and the HCV impeded my recovery.

36. I was referred to the Liver Unit at St James's Hospital in Leeds and I was under the care of Dr Jones. He explained what HCV and cirrhosis were and also explained the risks of having these conditions. He provided advice on treatment options and also spoke about precautions to take in order to reduce the risk of transmission to anyone else. He told me that I have stage 3 cirrhosis which had been caused by the HCV infection.

37. Dr Jones also spoke about GRO-C
GRO-C
GRO-C

38. I was really unsure about how I had contracted HCV for a long time and wanted to look into my medical history to see if any of the treatment I had had over the years could be linked to the HCV. About 6

years ago, I asked St James's Hospital if I could go and view my notes at the hospital, as I could not afford to request copies of my notes at the time. I took a notebook with me to jot things down.

**39.** When I was given my notes to view, I was shocked that my notes also contained the notes of a complete stranger and some of my mother's very personal medical records that she definitely did not want me to see. This seemed such a breach of confidentiality and my mother was extremely upset by this.

**40.** When going through my notes, I found the notes for Rebecca's birth and I saw that I had been given 'FFP' which I now know to be Fresh Frozen Plasma. I felt rushed when viewing my notes but luckily I had noted this down. When I went home and looked up 'FFP', I realised that I had received plasma after the birth but I had never been told this.

**41.** Following my visit to the hospital to see my notes, I got a call from Dr Cooper who had been my doctor when I had cancer. She asked me if everything was okay and mentioned that she had been informed that I had gone to see my medical notes. I was quite shocked by this as I have no idea who would have told her this. I didn't tell her anything specific and she told me to get in touch if I needed anything. Looking back, maybe she was concerned that I was researching some failings with my care.

**42.** More recently, I have requested and received my medical notes from St James's Hospital. It took me around 8 hours to go through them all as there was such a large stack of notes. However, the notes were all jumbled up and in a completely different order to when I saw them in the Hospital. In additional, the notes about Rebecca's birth and the FFP received were not included. My mother's notes as well as the stranger's notes have been taken out.

**43.** I have no idea why they had taken out the information about Rebecca's birth and the plasma I received but it does seem suspicious. I am going to get in touch with my GP to see if they may have a copy of the notes from Rebecca's birth and enquire with the hospital if they had left this note out by error. It just seems very strange that I got a call from Dr Cooper after viewing my notes and now very specific notes have vanished.

**44.** Looking back, the only link I can make to the HCV infection is the FFP I received during Rebecca's birth. I have never been an intravenous drug user or been involved in other high-risk activities. Therefore, I strongly believe the route of my infection was as a result of the FFP I received following Rebecca's birth.

## Section 3. Other Infections

**45.** I do not believe I have been infected with any other infections.

## Section 4. Consent

**46.** As far as I am aware, I was never treated for the purposes of research. However, I do not believe I was informed before being given FFP during childbirth and I was not asked to consent to this or told about any of the risks. I did not ask about the treatment I was being given as I trusted the doctors and nurses and believe they would look after me appropriately. I believe they should have informed me of the risks of the FFP and given me the option to consent or not consent to the treatment.

## Section 5. Impact

**47.** Being diagnosed with HCV and the resulting liver cirrhosis I have suffered, has had a major impact on my life. It has had an extremely negative effect on my mental and physical well being.

**48.** Having HCV always felt like something I couldn't share with people and it felt like a 'dirty secret'. It felt like having HIV which was extremely stigmatised and it made me extremely depressed. I went through a stage where I didn't want my toothbrush being touched by anyone and I put bleach on myself when I had a cut. I still have 15 bottles of bleach in my cupboard and I am still mentally affected by the impact of being diagnosed with HCV.

**49.** I became a reclusive person for quite a while following my diagnosis which is the opposite of my personality. I was just too embarrassed to tell the truth about my infection to family and friends.

**50.** After being referred to Dr Jones at the Liver Unit at St James's Hospital, I was offered treatment for the HCV. This would consist of 6 months of taking injections of Interferon and Ribavirin. I would also need regular blood tests in order to monitor my condition. I was told I would have a liver nurse specialist to help support me.

**51.** When I met the specialist nurse for the first time, we discussed the treatment I was about to start. She told me that while on the treatment I might have some weight loss, (In fact I lost 3 stone) and that might make me feel quite depressed. Although I have suffered with mild depression on and off my whole life, I told her that I am a positive person and I should be okay. She told me 'you will either want to kill someone or throw yourself off a bridge' which was quite shocking to hear. I told her I had been through cancer treatment and survived, as I have children to live for, so I was sure I would be okay. However, she said this treatment would probably be worse than chemotherapy and this scared me.

**52.** I remember I started taking the injections on a Tuesday and took them every Tuesday for six months; even now I hate Tuesdays because of this. The day after the first injection I started to feel sick and shivery and didn't think I would be experiencing side effects so quickly. It continued until around Sunday and then I had to have the next injection on the Tuesday and it all started again.

**53.** The treatment made me exhausted, gave me headaches and I felt shivery all the time. I didn't want to see anyone apart from my partner Darren and the kids. I stopped speaking to most of my family and friends. Even using my phone to call someone would give me a headache.

**54.** I think a lot of my friends and family thought the cancer had returned and didn't want to pry. I was disappointed that some of my friends hadn't come to support me but later one of my friends said 'I thought you were dying and I was scared to see you like that'.

**55.** I did cut out everyone but I think that was mainly linked to the shame of having HCV; I had no idea how I had acquired the infection at the time and didn't know how to explain it. I didn't want to tell people what treatment I was having but I also felt guilty that they thought it was cancer again. I would say there was something wrong with my liver but not give details. This was very unlike me as I am a very open person but it felt shameful to say I had HCV.

**56.** The HCV treatment also caused my hair to fall out, leaving me with bald patches. I decided to shave all my hair off as a result and I think this further solidified the idea that I must have cancer again in some people's minds. I now know that the HCV treatment I was having worked similarly to chemotherapy and this is why I suffered hair loss.

**57.** I remember my kids seeing me with my bald head for the first time and laughing, but they said it looked nice on me. I was expecting them to be shocked and upset by my bald head but I suppose they were just kids and didn't really understand what was going on. Since then I have shaved my head again to raise money for the Princess Trust.

**58.** I remember one day during my treatment, a lady from GRO-C Beryl, had come to pick up the kids to take them to GRO-C and came into the house. She knew I had been unwell but when she saw me she was shocked by my condition. I had been sleeping on the sofa and I had a sick bucket next to me. She said the room was far too hot, but I felt freezing cold.

**59.** Beryl said she had no idea how unwell I was and that I should have reached out to her before. She became very supportive and said that she would get GRO-C to offer their assistance too. I remember she got some cleaners from GRO-C to come in to help tidy up and they would do things like prepare tea for the kids. Beryl would have the kids for tea a few times a week during that time and said I could always speak to her if I needed something. She was one of the first people outside close family that I told about the HCV.

**60.** Halfway through the treatment, I became so unwell I wanted to stop taking the injections. I felt extremely sick and weak and felt like smashing my head against a wall. My partner at the time, Darren, took me to hospital and found me a wheelchair as I was too weak to walk.

**61.** When I got to the Liver Unit, Nurse GRO-D told me it wasn't my day to be seen. I had tried emailing her and calling her but she hadn't responded and I told her this. I told her I was going to stop my medication as I couldn't cope with the side effects anymore.

**62.** The doctor did see me that day and I told him that I couldn't deal with the severe side effects and that I felt like throwing myself off a building. I didn't want to see anyone and even my kids were tip toeing around me and were uncomfortable to come into my room in case I would shout at them. My relationship with Darren was going downhill and we had started arguing a lot.

**63.** The doctor was concerned about me wanting to stop the treatment and showed me how the treatment had been improving my bloods and why it was vital that I continue the treatment. I wanted to get better so I decided to try and continue with the injections, despite how awful I was feeling.

**64.** I started speaking to GRO-C from the Hep C Trust who shared her HCV story with me. I think I spoke to her about 3 or 4 times in total. I had been unhappy with some of the treatment I had received after my diagnosis and she told me it didn't matter how I had contracted HCV, I should be treated with respect. I told her about the side effects of the treatment and how I felt. I couldn't focus on my partner or kids and she was understanding of what I was going through.

**65.** GRO-C told me that her HCV had not cleared the first time she had the treatment and she had to be treated twice which was quite concerning to hear; I had never considered it a possibility that it might not work and the thought of having to do it all again terrified me. I think I should have been informed that there was a possibility of it not working when I started the treatment.

**66.** Someone at the Hep C Trust told me about a support group in the area which I tried to go to. I remember the address took me to an area under a bridge and I saw a group of people that looked like drug addicts standing around. I was pretty sure I had been given the wrong address and told the lady who had referred me that I hadn't been able to find it. It was only later that I realised that that was the support group and that a lot of people with Hep C were drug users.

**67.** I felt there was absolutely no support given to me by the hospital at all, even though they knew I had a big family with young kids to take care of. My Liver Specialist Nurse, GRO-D, used to say to email or phone her whenever I needed but when I did, she rarely responded. Even after I finished my treatment and I contacted her a few times with concerns about an infection, she seemed to brush me off or just ask me to seek advice from my GP. I was promised support from her and never received it.

68. After completing the course of HCV treatment with great difficulty, I was told I was clear from HCV. GRO-C

GRO-C

GRO-C

69. After my 40th birthday, I thought I would be single forever but I met David. We connected by speaking about our dogs who both looked very similar and could have come from the same litter. I felt like he was sent at the right time in my life and he has always been very supportive of me. I told him about the HCV before we started a relationship as I wanted to be open with him and he was fine about it. We have been married 5 years now.

70. Unfortunately, clearing the HCV was not the end of my health problems and I feel like my life is one big medical complication. Around 7 years ago, I suffered from septicaemia. I had gone out for the evening as my kids were staying with friends and I felt unwell after coming home. I remember I had had a few cocktails and felt a bit sick; I put this down to the fact that I rarely drink. I sat down at home and I started feeling really unwell. It felt like it went from 0 to a 100 so quickly. I stood up and I started haemorrhaging and vomiting. I called an ambulance and was taken to hospital. I remember when I was in the ambulance, I told the paramedic that I felt something between my legs. The paramedic said he wasn't a gynaecologist and wasn't going to check.

71. When I arrived at St James's Hospital, I was taken straight to a ward. The doctor treating me, told me I had haemorrhaged from my cervix. I remember my blood was tested multiple times and my white blood

count was so low they told me I probably had leukaemia. I panicked so much hearing this that I called my mum and told her straight away.

**72.** The doctor should not have said that I probably had leukaemia with no confirmation of this. I have had consistently low platelets since my cancer treatment and HCV treatment and they seem to not rise above 125. This is something that should have been picked up on before assuming I had leukaemia. In the end, I was diagnosed with septicaemia and I was told that it was rare to survive it. I have also suffered a further haemorrhage on another occasion, after doing some gardening, which also resulted in a hospital visit.

**73.** Around 5 years ago, I was diagnosed with Raynaud's disease. I was in the bath at my husband David's house in Sheffield when I realised my toes had turned black. I panicked and called for an ambulance. The ambulance was unable to get to the house due to heavy snow and asked me to call my GP to assess if I needed to come into hospital immediately. The GP said they believed it was Raynaud's disease and this was later diagnosed in person. This, along with the lymphedema in my legs, causes a feeling like I've rubbed against some stinging nettles and is very uncomfortable.

**74.** As the HCV has caused stage 3 liver disease, I need regular monitoring and scans. They also found 2 nodules on my liver around 2 years ago. I was told if the nodules turn cancerous, I will need a liver transplant.

**75.** Nurse GRO-D told me that I had to start having a procedure done where a camera is inserted down my throat. She didn't really explain why I needed this done, only that this needed to be done every 2 to 3 years to monitor my health.

**76.** The first time I had the procedure done, the medical staff were really nice but I was extremely traumatised by the whole procedure and it was very uncomfortable.

**77.** The next time I needed the procedure done, I told them I needed to be sedated so I didn't go through the same thing again. I have always had trouble with my veins and being cannulated, and this time was no different. I felt like the doctor was really pressuring me to have the procedure done without sedation and in the end, I agreed.

**78.** After I had agreed to have the procedure done without sedation, the staff were once again very nice but I was traumatised and cried for ages after it was done. I remember there was an old lady sitting next to me in the waiting room who asked if I was alright. When the nurse saw how upset I was following the procedure, she said at least it was better than dying of some stomach and gut condition linked to the liver and HCV. She said this in front of the old lady, disclosing my medical information to a stranger. This was the first time I even realised why they were doing this procedure.

**79.** Originally, I was told I would need this procedure done every 2 to 3 years, however, it has now been changed to once a year and I'm not sure why this is. I do not feel like the doctors or nurses try explaining my treatment to me or help me understand what's going on.

**80.** I have to have blood tests every 3 to 5 months in order to check my platelets. My platelet count was higher when I was having chemotherapy than they are now. My immune system is very low and I am more susceptible to catching infections, which happens regularly.

**81.** I have always suffered from mild depression which I put down to my lifestyle and relationship issues. This intensified significantly during the HCV treatment. In addition, I now suffer from anxiety and trust issues. I believe all the health complications have caused me some form of undiagnosed personality disorder. How I deal with other people and how open I am, has really changed.

**82.** I also still suffer from 'chemo fog' and I am aware that this type of 'brain fog' can be linked to HCV and its treatment as well. This makes it hard for me to remember things and recall dates.

**83.** The stigma associated with having HCV has definitely affected my mental health problems and I have experienced this stigma from family and health workers.

**84.** When I left the appointment where I was told I had HCV with my mum and my sister, mum told me not to tell anyone that I had been diagnosed because of the stigma attached. My mum has never addressed or spoken about the HCV since. I never felt like I had an opportunity to talk about the HCV as a result and this was such a contrast from when I had cancer. With the cancer I felt like I had so much support and with HCV I had nothing.

**85.** Some years ago, I had a fever of over 40 degrees and cellulitis in my legs. Blood tests indicated my platelets were very low and I was admitted to hospital for intravenous antibiotics. The nurse treating me gave me a dirty look and asked me when I had been a drug addict. I told her I have never been a drug addict and she said 'don't you have HCV?' I was clear of HCV by this point and I told her 'no, I don't have HCV and you shouldn't have assumed I was a drug user'. I was very upset by this incident and refused to be treated by her again. I felt like if the medical professionals were treating me with so much stigma. I questioned how other people would treat me if I told them I had HCV.

**86.** On another occasion, my partner at the time called me an ambulance as I was vomiting badly. The ambulance took a long time to come and when I got into the ambulance, they told me they had been waiting at the top of the road for about 15 minutes as they thought I had a gun or knife and needed police back up. They said they only ended up coming to me without the police because my partner had called back and said my condition was getting worse.

**87.** This story by the paramedic just made no sense and eventually he admitted that they had been told I had HCV and needed time get ready with gloves and aprons to protect themselves; this was the reason for the delay. My partner and I were so shocked by this and the fact that they endangered my life because they had heard I had HCV. I have no idea how they knew I had HCV because my partner hadn't told them and I was clear of HCV by this point. The stigma towards HCV felt shocking.

**88.** On a further occasion when in hospital, I was staying on a ward for older ladies due to my mobility issues and I was enjoying chatting to all the other patients. A nurse came over and started packing up my things and told me I was moving to a side room on my own. I told her I was happy where I was but she insisted that I move.

**89.** After I was moved to the side room, I was left alone for 4 hours. I had tried to call out for someone and ring the buzzer but no one had come. I needed to go to the bathroom and was unable to manage on my own with the drip in my arm and I wet myself.

**90.** When a hospital worker came in with my dinner, I asked her to call a nurse for me. She put my food on a table in the corner of the room and I asked her to bring it closer to me as I couldn't get over there. She said she had been told not to go close to me due to the infection, which was very upsetting.

**91.** When the nurse finally came in and put her gloves on, she was very rude to me and said that I was being kept separate due to the HCV. I got very upset and emotional about this and told her I had been treated like a leper. I told her I was leaving the hospital and refused to stay there. I said it was bad enough having a big orange sticker on my blood test cards but this was too much to deal with. The Nurse realised how upset I was and took her gloves off and apologised to me. However, the damage had been done and I was extremely upset by how badly they could treat me just because I used to have HCV.

**92.** I have always had difficulties with cannulation due to my small veins, as mentioned above. Even though I always tell doctors and nurses about this issue, I never feel like they take me seriously. On one occasion when a nurse couldn't get a cannula in, I told her that I needed to drink some water and maybe soak my hands in warm water to help the veins show better. She completely ignored me and pricked me all over. She tried about 9 times before I told her to call a doctor instead. When the cannula was finally in, it didn't feel right and I told her not to flush it. She said no it just needed flushing and it ended up going back in her face and blood went everywhere. This issue and the fact that I am never listened to has made hospital visits significantly worse for me.

**93.** I feel like the bad experiences I have had with doctors over the years has really affected my trust in the medical profession. Once I attended a group session called 'let's meet' where Dr GRO-D was hosting a Q&A session at the hospital about cervical cancer. I asked a question about whether being promiscuous in your youth could cause HPV and lead to cervical cancer. I remember in front of about 100 people she said, 'yes and that is probably how you got it since you had a baby at 17'. I was furious at what she was insinuating.

**94.** I have been unhappy with some of the GPs I have seen at the Newton Surgery in Leeds. My first GP, Dr Hungen, was really nice and I also see Dr Khan who is an asthma specialist and is also good. However, I have been very disappointed with the care I received from Dr GRO-D. She tests me for STDs at every single appointment which is extremely unnecessary as I am not in an at-risk group. In addition, she always talks about the hysterectomy I have undergone, whilst I have never had a hysterectomy. It is frustrating as she always begins treating me as if I have had a hysterectomy, when I have corrected her on numerous occasions.

**95.** I have also struggled with the nurses at the Newton Surgery as it feels like I am dealing with a new nurse every time I go in. This is what led to my lymphedema treatment being halted, which I described above. If I had consistently seen the same nurse, she would have understood my condition, rather than decisions being made about my care without knowing me or my health conditions.

**96.** Due to the bad treatment I had received at the surgery and during my HCV treatment, I spoke to Advocate, a legal help service, about getting an apology for what happened and they were the ones who told me about the Infected Blood Inquiry.

**97.** Even our chemist has been rude to my husband and me on a number of occasions. I remember once I badly needed some antibiotics and he told me he didn't have them at the moment. I asked whether they could be delivered as I don't live near the chemist and have issues with mobility. He then found a pack of the antibiotics and actually threw the packet at me. I was shocked. My husband is very easy going and didn't want to cause an argument but I was very upset by this incident.

**98.** Having a nice doctor really makes a massive difference in your care and mental health. I remember a few years ago I had some tests done to my veins to check the volume in my legs. The doctor was so nice and kind to me and wrote a nice comment about me in his notes. He did not mention my weight or HCV and it made the whole experience so much better.

**99.** I have always struggled with my weight and as mentioned above, I ended up having weight loss surgery in 2011. I eat in the same way that a drug addict uses drugs. It is a comfort thing for me and I feel in control and empowered when I am eating. Even after the weight loss surgery, I still feel like I want to eat.

I do feel that the obesity has had a major impact on my diagnosis and my care. Every symptom I have had has always been put down to my weight and I believe my diagnosis was delayed as a result.

**100.** An example of things being put down too my weight is the back pain I have suffered for a long time. After receiving my medical notes, I saw that in 2005 my GP had written that I have a condition at the bottom of my spine. Having researched it, I know this is something you have from birth. This condition has caused me to shrink from 5'4 to 5'0. My grandmother also shrank and had a hunch later on in life and most likely had this condition too.

**101.** I was never actually told about this condition despite my medical notes saying I needed an MRI as soon as possible. I was never offered an MRI and all the GP told me was to lose weight and prescribed morphine patches. Clearly there was something wrong with my spine which had nothing to do with my weight, so why was this never followed up? Obesity became an excuse for doctors to use whenever something went wrong with my health.

**102.** I feel a lot of guilt about the impact my health has played on my children's lives. I have been in and out of hospital for many years. They have always had to live through the ups and downs of my illnesses and the terrible side effects of the treatments. I feel they have often felt like they were walking on egg shells around me, trying not to bother me with everything I was going through. I also missed numerous school plays, parents' evenings and sports days which I feel terrible about.

**103.** On certain days when I was so unwell with the HCV treatment, I couldn't even manage to take them to school and this could have impacted on their education. I wish more support had been offered to me at this time as it was so difficult to manage 6 children with the side effects of the HCV treatment. The hospital knew the position I was in but did nothing to help.

**104.** I feel that most of my children have dealt with it all very well and are strong. GRO-C GRO-C GRO-C I felt like I had failed as a parent when this happened and I think it is linked to my lack of availability during my ill health. GRO-C GRO-C GRO-C

**105.** I am very close to my children and grandchildren and spoil them as much as I can. I always tell them I love them and adore spending them with them. When my daughter Rebecca left home I needed to have counselling as I was so affected by it.

**106.** I told my children about this interview I was going to have with the IBI and showed them the notes I had prepared for it. I don't think they ever really knew exactly what was happening in terms of my health but now they have a better understanding of what I went through.

**107.** I have always made sure my children either worked or went through further education. I am very proud that they are all doing well and are self-sufficient.

**108.** I have never been able to work and now I depend on personal independent payments. My husband works full time and my daughter Amber acts as a carer for me and receives a carer's allowance. However, she is looking for a full-time job now and feels it would be best to stop caring for me so that it doesn't affect our relationship in the long term. My sister has offered to help out when she can.

**109.** I did try doing a 6-week course designed for individuals who had been unwell or had difficulties due to social issues. I said I wanted to be a florist and started a course at college which was one evening a week. However, I eventually left due to ill health and depression.

**110.** I feel like often I am really motivated and excited to do something and then suddenly I get down when I'm feeling unwell and depressed. I felt this way often when I was involved in charity work like getting a petition signed; I would initially be really involved and excited and then I felt like I had no energy to continue.

**111.**As I have never been able to work, I have struggled financially. I once even had to borrow money from a loan shark. We avoided paying one bill to cover a more urgent bill. I also have a very high heating bill as the Raynaud's disease and after effects of the HCV treatment make me feel very cold. Money isn't everything and if my family has everything they need I'm okay. If I have a spare £50 and a homeless person asked me for a £1, I'd give them £10. That's how I feel about money.

**112.**One thing that I strive to pay for regularly is reflexology treatment. It really helps me feel better but it is not something available on the NHS. I have told some doctors about it and some have laughed it off while others have said it is good if it works for me. However, it is really expensive so for my birthday or Christmas I ask for sessions of reflexology instead of presents as I cannot normally afford it. I believe it should be offered on the NHS.

**113.**I have struggled with social activities due to my poor mobility. My mum always used to say I should do a long walk everyday but she doesn't realise the pain and swelling it would cause in my legs. When on a family holiday to Blackpool, what should have been an hour walk across the pier took me 4 hours to do. I felt bad because I was in significant pain but I didn't want my kids to miss out on their holiday. I was in tears when I got back to the hotel.

## Section 6. Treatment/Care/Support

**114.**Although I was able to get care for the HCV, it was a very difficult process and I did not feel like I had the support I needed from the doctor or the specialist nurse I was assigned. It made the entire process much more stressful and difficult.

**115.**I am still struggling to get treatment for the damage to my liver caused by the HCV. I always have to chase appointments for my liver scans which I was meant to have every 3 to 6 months. I think now it is meant to be more like every 12 weeks as I'm so unwell.

**116.** Although I have cleared the HCV, as I mentioned above, it caused stage 3 liver disease and this needs monitoring as I have been told my liver is too far gone to repair itself. It is always so difficult to get an appointment and it is worrying when I can't get one. I have pains on my right side and it is obviously something I want to investigate.

**117.**Even in the last few weeks I have had issues as I was told my liver scan had been cancelled by me. This was obviously not the case and I told them there had been a mistake. Instead of just rebooking the appointment I had to speak to the consultant again. I try my best to do my part by being healthy and not drinking alcohol but it is hard when the medical professionals don't provide you with the support needed.

**118.**I have never been offered counselling to help me cope with being diagnosed by HCV infection, its treatment and the fact that I have such severe liver disease. The lack of psychological support made having the HCV treatment much more difficult than having cancer treatment.

## Section 7. Financial Assistance

**119.**I have never applied for any financial assistance in relation to my HCV infection.

**120.** Once someone from adult social care came to visit me and I remember he mentioned the Skipton Fund, but this was before I even knew about my route of infection. I remember he was a grandparent of one of the children at my kid's school and I felt uncomfortable about this. I was embarrassed and wanted to keep things private so I have never really looked into financial compensation.

**121.** I am now aware of the EIBSS and the fact that I can make an application to them. I am also going to re-request my medical records from both the hospital and GP and specify that I want the records from Rebecca's birth that mention FFP. I know I have seen these records and that they do exist.

## Section 8. Other Issues

**122.** I want to share my story as I really believe the HCV and liver damage should have been picked up far earlier. I had abnormal LFT results when I had blood tests done but all the symptoms I had were put down to other things like my weight. I know I was once tested for Hepatitis B, but why was I never tested for HCV? How could this have been missed for so long, especially given all the tests I was having due to my cancer diagnosis?

**123.** My condition cannot be reversed and I know I won't live as long as I may have done. However, I want to draw attention to this failure to diagnose me early so that in the future doctors don't miss these symptoms in other people. The sooner a diagnosis with HCV can be made and treatment given, the less damage there will be to the liver.

**124.** I have tried to consult solicitors in the past to speak about the bad treatment I have received over the years but I have always been told I am too late to pursue a negligence claim. That is why it is so important to me that the Inquiry hears what kind of treatment I received following my HCV diagnosis. I just want someone to believe what I went through.

**125.** I also want to highlight the complete lack of support I had when going through HCV treatment and how difficult this made my life. Although I had a lot of support when I had cancer, I should have felt this support with the HCV too. To this day I face difficulties and stigma when accessing treatment for the liver cirrhosis caused by the HCV. I hope that by sharing what I went through there will be more support for people going through HCV treatment in the future.

**126.** I want the inquiry to find out and disclose the truth about what really happened with infected blood and I want people to believe what I knew all along was true. I also want an apology and for people to learn from their mistakes.

**127.** I believe God has kept me on this earth for a reason. I have survived cancer, HCV, sepsis, weight loss surgery, a ruptured spleen and so much more. I hope my story can help make a difference as to how things are done in the future.

## Statement of Truth

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

Signed GRO-C

Dated 17/02/21