

Witness Name: Janice Whitehorn-Cox

Statement No.: WITN2000001

Exhibits: WITN2000002 -

WITN2000011

Dated: 7 August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JANICE WHITEHORN-COX

Section 1. Introduction

1. I, Janice Whitehorn-Cox, will say as follows: -
2. My date of birth is GRO-C 1979 and my address is known to the Inquiry.
3. I live in Bedfordshire with my husband and am self-employed.

Section 2. How Infected

4. My mother, Daphne Whitehorn, was infected with Hepatitis C ('HCV') in 1973 when she received a blood transfusion during a kidney transplant. I believe I was infected either in her womb or during my birth in January 1979 at Paddington Hospital, London, via blood to blood contact. My mum was diagnosed with HCV genotype 2, the same type as mine.

5. I understand my mum received no information or advice at the time of her infection with HCV about the risks of infected blood.
6. Mum found out she was infected with HCV 23 years later, in around 2001, when a nurse was taking her blood. At that time mum had routine blood tests for her kidneys. During one of these tests the hospital had tested her for HCV without her knowledge or consent and that is how she found out about the infection.
7. When mum was told she had HCV she was given very little information about the infection and no support. It was briefly mentioned that my dad should get tested and possibly the children too.
8. I was 22 years old at the time and had just moved to Liverpool on my own to go to college. My mum had to tell me about her infection over the phone, which upset her greatly. I went to the GUM clinic and asked to be tested for everything and assumed this would include HCV. The test came back clear so I believed I was not infected. I would later find out this was not the case as, at that time, they did not routinely test for HCV, just HIV and Hepatitis B.
9. I believe that at the time I requested blood tests from the GUM clinic it should have been compulsory for those tests to include a HCV test or, at the very least, for those people who may have been exposed to the virus to have a letter requesting such a test. The government ought to have taken responsibility for what to do next: not to leave it up to my mum and me to try to work it out for ourselves. I also believe that there ought to have been someone to talk to you in person regarding the possibility of HCV infection. The possibility of being infected is very scary if you know nothing or everything about this disease.
10. HCV is a slow disease which usually only manifests with visible signs between 15 and 20 years after you become infected. Up until this point, at around 22

years old, I had not noticed any visible signs of infection, but I then began to get very tired, which I now understand to be chronic fatigue. I was so tired that I went to see my GP in around 2001 and took my boyfriend at the time with me, as I had always been a very shy and anxious person and would not have gone to the GP for anything unless I was desperate. My GP did not do a blood test and told me it was just because I was a young adult. I had a 'normal' if not slightly low BMI at this time (this is relevant to the issue of my weight gain later on) and nothing more was done.

11. Over the next few years my health continued to decline very slowly but I adjusted to the symptoms and to feeling very tired. I was struggling to keep in employment because I had good days and bad days, so I set up my own business so I could work long hours when I felt well, and sleep on the days I couldn't manage to work. I met my husband during this time and he looked after me a lot.
12. From 2005 to 2009 I visited my GP around 13 times with symptoms of chronic fatigue, sickness, headaches, stomach problems, weight gain, hair loss, nausea, joint and muscle pain, constant flu like symptoms and chest infections. I now know all these symptoms are associated with HCV. I had two blood tests during this time but neither tested for HCV. I even took my mum with me to one appointment and she said to my GP, Dr [GRO-D] of [GRO-D] [GRO-D] that she had HCV and it was possible that I did too, explaining that it was transmitted blood to blood. Dr [GRO-D] dismissed this and, although a blood test was taken, it was not tested for HCV. Each time I was told that my problems were due to my weight, which was increasing regardless of the exercise I was doing (which was a struggle due to increasing joint and muscle pain, and constant sickness).
13. It was not until 2015, having given up going to the GP since 2009, that I returned to my GP as my husband and I had been trying and failing to

conceive for five years. This time we both attended the same surgery and we saw a Dr GRO-D Routine bloods were taken.

14. I then received a telephone call from my GP and was told that I had HCV. Just like that, no more information, and no help or guidance. I think this was the worst possible way to give this news to someone and I am appalled that my GP thought this was an appropriate course of action. I should have been called in and told in person, with support and information. I have never been given any support, and am now in private counselling to deal with this as it has left a lot of mental scars for me.
15. I have requested my GP records in order to assist with this statement and am still waiting to receive them.
16. I received a referral letter for the hepatitis clinic at the Luton and Dunstable Hospital. I was called in to the clinic for more blood tests to confirm the diagnosis of HCV. I had an appointment with the hepatitis consultant, Dr Khanna, at Luton and Dunstable. I was given no information on managing or understanding the infection, I was just told once again, with no thought or understanding, to go and lose some weight. I was given no information about the risk to others of my infection and was not advised that my husband or previous partners should get tested.
17. The letter from this appointment, dated 18 May 2015 **[WITN2000002]**, which records as follows, 'I saw this lady with her mother and her husband in clinic today, thank you for referring in. She is 36 years old: she was having some fertility tests done recently and was found to have Hepatitis C. She [is] otherwise fit and well. She is on no regular medication. She lives with her husband. She does not smoke and only drinks about a bottle of wine over the course of a week and not regularly. Her mother has Hepatitis C, which she caught as a consequence of a blood transfusion at the time of renal transplantation prior to 1992. She does have tattoos, which have always been done at professional places and she also has piercings which have been

similarly done. She has never injected drugs.' The letter sets out a management plan for HCV of a liver screen, Hepatitis C genotype, ultrasound scan, biopsy and review in clinic with regards treatment. The letter then says, 'I have informed her that she can carry on with her fertility treatment and if she was to get pregnant, we will just simply defer treatment [until] after her baby was born'. I was indeed given this advice about the plan for a liver screen, ultrasound and biopsy, but I was certainly not offered treatment for HCV at this stage (I have set out below the difficulties I experienced in getting treatment for HCV).

18. At the same time I was also referred to the fertility clinic. A referral letter [WITN20000003] from Dr Thit Thit to the Fertility Services on 10 April 2015 which says, 'they have been trying to conceive for the last 5 years. She was seen by one of my colleagues who arranged blood tests. Unfortunately Hepatitis C was positive and she has been referred to the Liver Clinic'. At this appointment I was told, this time in person, that I had type 2 diabetes. The two diagnoses, of HCV and diabetes, absolutely floored me.
19. I can now see from my medical records that the fertility clinic asked for information about my HCV from Dr Khanna, who replied on 28 October 2015, [WITN20000004], stating: 'thank you for writing to me about this lad[y's] fertility treatment. She has Hepatitis C, she is unlikely to have any cirrhosis of the liver. In an ideal world, we would like to get on and treat her Hepatitis C, but this can certainly wait till such a time or when her fertility issues have been sorted. Alternatively, we could treat her with PEG/Ribavirin for 24 weeks, she would avoid pregnancy for another six months following treatment due to teratogenicity and then re-start her fertility treatment. Certainly from a Hepatitis C point of view there is no urgency to start treatment as yet, I am waiting for her liver biopsy, after which I will review her in clinic.' I am shocked that Dr Khanna felt able to suggest delaying treatment whilst I tried to conceive with no mention of any risks of HCV to a baby. I am equally surprised that her opinion was that it would be fine to wait to treat me when she had not yet had the results of my liver biopsy, in fact, I had not at that point even had a biopsy.

20. There then follows, a letter from Dr Khanna to my GP dated 3 November 2015 [WITN2000005], saying, 'This lady has still not had her liver biopsy. I am not sure exactly why that is. I wonder whether it was an error on my part. I will chase this up. I will try and get the liver biopsy to happen soon. I will see her with the results of the biopsy within two or three weeks afterwards. If she does not have significant scarring and only moderate activity, then she can safely delay her antiretroviral treatment until her fertility issue has been sorted'. This response from Dr Khanna seems more appropriate because this time, one month later, she says she needs to see the results of the biopsy before advising whether it would be safe to delay my treatment.
21. In my medical records there is a copy of a letter I sent to Dr Khanna on 30 November 2015 which describes my feelings about treatment and conception, and where I ask to be considered for treatment as soon as possible [WITN2000007].
22. A letter from 17 December 2015 from Dr Khanna to my GP explaining that the November 2015 liver biopsy showed mild portal inflammation and advising that there is no cirrhosis [WITN 2000006]. The letter states 'I explained there is a 5% risk of transmission of Hepatitis C to the baby. She would like to have treatment before she tries to conceive. Of course there is a timeline to all of this. I will try to see whether we can expedite her treatment.' As a person who has contracted HCV myself in this way, from mother to daughter, I have first hand experience of transmission of the virus via this route and so I feel percentages like this are meaningless: I would never, ever put a baby at risk like that and am appalled that it was suggested as an option for me.
23. A letter of 10 February 2016 to my GP from the fertility clinic explaining that they were discharging me back to GP care pending my HCV treatment and me achieving a lower BMI [WITN2000008]. The consultant gynaecologist explains in the letter that 'this [HCV] treatment needs to be started as soon as possible'. The letter explains the team would only offer fertility treatment when I achieved

a lower BMI, was still under 40 years of age (at the time of writing I was 37) and the hepatology team were happy for me to undergo fertility treatment.

24. At no point, either at that first appointment or subsequently, or when I had a liver scan, liver biopsy or further blood tests, was any help or information about HCV given. The only reason I had any knowledge about HCV was because my mum had it, and the rest I had to find out through online research.
25. I strongly believe information should have been provided to both my mum and me much earlier. Mum should have been given full information once the hospital were able to confirm in 2001 they had given her the infection in 1973, if not some time before 2001 as they had tested her before she was told, without her knowledge. She should also have been told about the risk to others, and my dad, brother and I should have been called in to the GP surgery for testing.

Section 3. Other Infections

26. I do not believe I have been infected with anything other than HCV as a result of mum being given infected blood.

Section 4. Consent

27. I do not believe I have been treated or tested without my knowledge or consent, without being given adequate or full information, or for the purposes of research.

Section 5. Impact

28. From a mental perspective, I have suffered with brain fog, anxiety, nervousness, low mood, irritability and mood swings as a result of being

infected with HCV. I have also suffered with the guilt of knowing that for 36 years, when I didn't know I had this virus, I could have passed it on as a baby, as a child through a cut at school, or at any later point in my life through intimate contact or through medical or dental care. I have had to sit down and think through all the possible situations in which I could have done this, the implications and the guilt that sits with this. I found this unbearable for a very long time.

29. From a physical perspective, I have experienced constant nausea, extreme tiredness, flu like symptoms, joint and muscle pain, especially in the hip and leg area, restless legs, headaches, weight gain, hair loss, indigestion, stomach problems, bloating pains in my tummy, insomnia, dry eyes, skin rashes, itching, allergies, skin sensitivity to bites, etc, low immunity, hot sweats, and sensitivity to hot and cold.
30. In terms of further medical complications and conditions that have resulted from the infection, I have developed type 2 diabetes. I was given this diagnosis at the same time that I received the diagnosis of HCV. The GP was far more concerned about my diabetes and at no point showed any concern or thought for the HCV, just that I had given myself diabetes by being overweight. I was called in for meetings about my diabetes and given medication and a lot of advice (which was not always correct), but at no point did anyone make the connection between HCV and diabetes. None of the blood test forms for diabetes had 'risk of infection' stamped on them, unlike all the blood testing sheets I had to give for HCV testing. This meant that every time I had to have a blood test for diabetes I had to explain that I had HCV and was an infection risk, which was upsetting and humiliating.
31. I declined medication for diabetes as I believed it was caused by the HCV and the stress of the diagnosis. I managed to control my diabetes with a very strict diet, an exercise programme and regular blood tests to keep it in check. These tests also demonstrated that when I was 'clear' of HCV my diabetic

numbers were normal, and when the HCV came back, the diabetic numbers went high again. When the HCV cleared once again, and has stayed clear, my bloods for diabetes are normal and not diabetic. There have been studies on the correlation between type 2 diabetes and HCV but my GP dismissed the link.

32. I have also been unable to conceive after ten years of trying. I have no evidence on what has caused this; it may or may not be HCV related. The fertility clinic offered IVF as the only option. Based on my high BMI and my personal choice to decline, we did not go down this route. I was told I could continue to try to conceive naturally whilst still having HCV. I knew the risk of potentially passing this on to a baby and then both myself and the baby needing to have treatment. I knew I would not wish such treatment on anyone, let alone a baby, and did not feel it right to deliberately infect anyone, yet this is what the NHS were advising me to do (see above reference from **WITN2000002**). I have set out below the two rounds of treatment I went through to try to clear the virus so I could conceive naturally. The first round failed and, though the second round succeeded in clearing the virus, the whole process took several years and time was against me as I was only diagnosed at 36.
33. We started going through the adoption process but this was initially pushed back by eight months over concerns for my emotional state. I have found it almost impossible to talk about my past experiences with HCV and the treatment I received from my GP, which I must be able to do for the adoption panel. I find it incredibly traumatic to talk about the years and years where my GP dismissed my symptoms and blamed my age and my weight gain (which was caused by the HCV) instead of investigating the virus that was always there.
34. The adoption process has now been put on hold after 18 months of training, etc, as social services remain concerned about my mental state, in particular

my mistrust of the medical profession which I believe has been caused by years of being ignored by my GP. I have reassured social services that my mistrust of the medical profession would not affect my ability to seek help for any child I adopt, as I believe that my past experience would now enable me to stand my ground and ask for second opinions where necessary, etc.

35. I had an ultrasound scan when I finished treatment for HCV because I was still suffering with right upper quadrant pain. The scan revealed gallstones and I was advised that a cholecystectomy (gall bladder removal) might be needed in the future. I have been reluctant to accept surgery to remove my gall bladder both due to my mistrust of the medical profession and because GRO-C underwent the same surgery and nearly died due to his bile duct being cut by mistake. I have instead researched gall stones online and successfully got rid of them by drinking apple juice, which softens them, allowing them to pass naturally. I do not know whether the presence of gall stones is linked to my HCV or its treatment, but I have heard that they might be, though any link has been dismissed by my treating doctors.
36. I have suffered from skin lesions on my face and head for a number of years. Again, I do not know whether these are connected with my HCV or its treatment, but whenever I feel worried or stressed I pick them and the doctor has advised that this prevents them from healing.
37. Accessing treatment for HCV was extremely difficult. I was diagnosed at 36 and was refused treatment initially as I was not unwell enough (contrary to what is set out in correspondence at paragraph 17 above I was not offered treatment initially). After being refused treatment for a year and facing the option of trying to conceive naturally whilst being infected with HCV, I wrote to my hepatitis consultant begging for treatment. This was eventually granted but only because I wanted to conceive and was already 37. If I had not been trying to conceive I would not have been granted treatment.

38. I had originally been granted treatment with Ribavirin and Sofosbuvir for a course of three months. This is a short treatment and is proven to be much more successful in its cure rate, with fewer side effects, than treatment with Interferon and Ribavirin, but I was then told I was not eligible for this treatment as it was too expensive. Instead I received treatment in the form of pegylated Interferon and Ribavirin in weekly self injections for six months in 2016, ending in August 2016. A letter from Dr Khanna to my consultant gynaecologist dated 21 February 2016 [WITN2000009] explaining, 'Janice is due to commence treatment for her Hepatitis C very shortly. Unfortunately she does not have cirrhosis which means that she is not entitled to the newer drugs with a shorter duration of treatment, however, she has a very good genotype of Hepatitis C and she has an above 80% chance of responding to treatment. I am hoping that we can shorten the duration of her treatment to 16 weeks, however, for six months after Ribavirin therapy she is going to be unable to commence [fertility] treatment as the Ribavirin can be teratogenic and needs six months to wash out of the system.' I am dismayed at the way this letter is written, 'unfortunately she does not have cirrhosis'.
39. The virus was undetectable at five weeks post treatment and I asked to be re-referred to the fertility clinic. However, within 12 weeks of clearing the virus, it returned. This caused a lot of physical and emotional trauma. In tears, I again wrote to my consultant asking for the shorter treatment as I was self-employed and would not get paid leave during another six months of treatment. I was told I had to wait six months to go on a second round of treatment with Sofosbuvir and Ribavirin, this time for three months. Again, I was only offered this treatment because I was trying to conceive. I wish this treatment had been offered to me in the first place: it might have worked first time round, saving me precious time to attempt to conceive naturally having cleared the virus. As it was, I was 39 when I received the all clear, one year after treatment had ended, and had lost over three years of trying to conceive from diagnosis at 36.

40. Both treatments were similar to chemotherapy and I suffered side effects of weight loss, hair loss, low mood, nausea, flu like symptoms, extreme tiredness and muscle pain. It was very like the HCV symptoms but magnified. I also suffered with teeth pain and felt very angry and aggressive for the duration of both treatments and for 12-18 months after. I have been left with memory loss, short attention span, an inability to concentrate, a lack of empathy and a tendency to swear a lot, something I have noticed in other HCV sufferers post treatment, including my mum. My medical records describe side effects during the first round of treatment including tiredness, nausea, loss of weight, some disturbed sleep, dry skin and flu like symptoms, mood swings, itching, stomach cramps, dry eyes, breathlessness, chest pains when exercising, bruising to veins on legs, and constipation. My medical records describe side effects during the second round of treatment including fatigue, irritability, anger, rage, breathlessness, chest pain, disturbed sleep, nausea and brain fog, headaches, and a dry, sore nose. These records are available on request.
41. I have now 'cleared' the virus and was told in June 2018 that, at one year post treatment, I had a sustained virological response. A letter confirming this [WITN2000010], and it notes, 'Her HCV virus is not detected. That mean[s] a sustained virological response. This equals having a cure. We believe the virus will not come back. She does however tell me that she continues to have a twinge in her right upper quadrant abdomen. We have booked an ultrasound scan to check this but we have also booked a fibroscan which will stage any liver disease. She tells me she is now taking up boxing and is doing a boxing match for cancer research in July. I have given her a letter to say that she is no longer contagious and her virus is now not detected. I have also warned her about other people's blood and coming in contact with that and that she should be careful. We will review her in three months' time and she will have both scans done.' When I started boxing I felt I should declare my previous infection, even though I was a year clear. I was asked to get a letter from my doctor stating I was not contagious, and had to inform my opponent. At this appointment with my specialist nurse she informed me not to come into blood

to blood contact or I would risk getting HCV again. I found this insulting because it felt as if she was suggesting I was deliberately putting myself at risk, and I felt blamed for having been infected with HCV previously, even though I had been infected, and my mother too, through no fault of our own. The feelings of blame seem to never go away.

42. I would like to note at this point that my specialist nurse was very aware how both myself and my mother had been treated by other medical professionals in relation to our HCV. She dealt with me regularly throughout my treatment and asked me to send her an email about how my mother and I had been treated by our GPs, so that this could go out in a newsletter to GPs, to help raise awareness of HCV.
43. The ultrasound scan revealed multiple small stones in the gallbladder and I wonder to what extent this might be related to the HCV, as mentioned above. The fibroscan in June 2018 showed a stiffness of 2.9. Correspondence from my Hepatitis C specialist nurse on 18 August 2018 explained that there is a less than 5% chance of my HCV returning.
44. I also saw Dr Khanna at this time and was a year clear of HCV. Dr Khanna did not recognise me and appeared to be shocked by my fitness, weight loss and how well I looked. I felt she had assumed that I had previously just been fat and lazy and that the HCV had no impact on my life. I was much more confident at that appointment than when she had seen me in previous years because I was feeling so much better, and I was able to say how I felt about how she had treated me in the past. I told her how angry I was at how she did not listen to me when I was first in her clinic, and how she had made assumptions about my lifestyle from the way I used to look, which, as she could now see, were not valid. She apologised and said that she could see that now and said her opinions of people with HCV had changed over the past year. I asked her not to make assumptions and judge people who have HCV, and not to assume they were either alcoholics or drug users (not that this should matter). I asked her to see in me the direct impact of HCV on a person,

as I had no other medical issues apart from HCV, so in me you can see the effects the virus has, both physically and mentally. I believe that, until that moment, she had not realised how much an effect the virus can have on its own. When I left the appointment I was pleased to have been able to talk to Dr Khanna frankly about these issues and grateful to her for her apology and her change of heart.

45. The letter to my GP from Dr Khanna after this appointment dated 9 August 2018, demonstrates this, 'It was an absolute delight to see Janice in clinic today. She is well in herself. She looks entirely different to when I saw her first. From a Hepatitis C point of view we are going to monitor her once more in a year's time at which point we will then discharge her. She has however had episodes of right upper quadrant pain and been found to have gall stones on the ultrasound scan. I would be grateful if you would consider referring her to the GI surgeons for this. I have asked her to come and see you to discuss this further.' [WITN2000011].
46. To be honest, I'm a bit gutted she hasn't had be me back as requested, in her last letter, from August 2018, saying come back for bloods in a years, as I say I did put my bloods in and got results via text from Nurse Tresse, but Dr Khanna never returned my call after leaving a message with her secretary requesting the results and an apt, as I would like her to see me now, two years post treatment. As I am different still, as have lost some more weight, am fitter and stronger and my hair has doubled in length and fullness, my skin is clearer, and I will never take any dr's BS , ever again. The meek sobbing 36 year old when she first saw me, no longer exists. I still don't know if this is a good or a bad thing, but it just now is.
47. I was discharged at this appointment in August 2018 and given a blood test form to hand in in a year's time. I have just done this and thankfully am still clear of the virus, but I did not receive an appointment and had to make the arrangements for this follow-up myself. I had to chase for the results of the blood test and leave a voicemail, eventually getting the results in a text

message, which seems to indicate a distinct lack of care about how results are communicated. I have made a copy of the blood test form myself, so I can have a test for HCV at any point if I feel the need to. This might sound strange but, through counselling, I have realised that I need to get some sort of control back over my life, as waiting for the GPs to do anything for the years when I was undiagnosed was a waste of time. I am still waiting for my follow-up appointment from Dr Khanna for August 2019, and I have rung her secretary to chase this up. There has been no aftercare or thought about this: the treatment now seems like the easy bit, it is getting over it all and getting on with my life that is still the hard bit.

48. As I can now exercise, eat properly and am in less pain (though I still suffer with very painful joints), I have lost 20kg in weight and my whole body is healing. I now feel physically much better and can finally put time into getting fit, which has resulted in me losing weight. After clearing the virus I wanted to be as strong and fit as possible, should the HCV ever come back.
49. However, the emotional side effects of the virus and two rounds of treatment remain with me and have impacted upon me massively, which I am now trying to deal with through counselling. I live in fear of the virus returning, and this has been an underlying and constant fear since treatment ended.
50. I faced many difficulties and obstacles in accessing treatments, as I have set out above. Neither my mum nor I were offered any treatment as we were told we were not ill enough for treatment. I was told that unless I had liver cancer I was not eligible and to wait until I did. Living every day like I was waiting to die was mentally very hard. I only had to deal with it for a few years, but mum had to manage this for over 20 years. During the time I was fighting for my second round of treatment we were also trying to get treatment for my mum. My mum was never offered any treatment despite us making an appointment to see her consultant and begging. She was told that as her liver cirrhosis was only 5, rather than the 12 needed for treatment to be granted, she could not start

treatment. Eventually, we wrote to her MP and somehow he managed to intervene to get her treatment started. Thankfully, she is also now clear.

51. We both had to fight for treatment and, had we not done so, we would not have got it. I believe we should not have been made to beg for treatment. The government should have been doing everything in its power to fix things by offering treatment to those infected, not only to save the NHS money from the illnesses infected blood has caused by clearing these infections, but also to stop the spread of infection unknowingly from person to person.
52. I believe my second round of treatment with Sofosbuvir and Ribavirin should have been made available to me, and others, immediately, as it has proved significantly more effective and with fewer side effects than Interferon. I also believe that there should have been more support and counselling before, during and especially after treatment.
53. I have set out the mental and physical effects of the treatments I have received above. Neither my mother nor I feel completely well after treatment. Over two years on from being 'cured' I have been unable to return to work as I now struggle to maintain concentration and my moods can be very low.
54. My infected status has impacted on my dental care because, since being diagnosed, I have been too scared to tell my dental practice about it so have not been to the dentist.
55. The impact of being infected with HCV on my private, family and social life is as follows. I was extremely worried I had passed it on to my husband. The assumption everyone makes is that it is an STD. Thankfully, my husband was not infected, but the virus has taken its toll on our relationship and we have reached breaking point on several occasions, from the trauma of the diagnosis, the rounds of treatment, the infertility. I behaved dreadfully towards him. I have felt crazy at times, which is incredibly scary. I have been overcome by

the stress and sadness of it all and there were times when I wanted to walk out. My husband is **GRO-C** and the stress from all of this has impacted on him a lot, both emotionally and physically. **GRO-C**

GRO-C
GRO-C
GRO-C

56. My family have suffered a lot of emotional stress, especially my parents. My mum tries to deal with the guilt of passing the infection on to me and the effect it has had on my life. She is also greatly affected by the virus, and we went through treatment at the same time. This was a huge amount for my dad to deal with.
57. There is a lot of stigma around the virus and telling people about the infection is difficult because they judge you and change how they consciously or unconsciously react to you. I found it very difficult telling my husband and former partners about my HCV because of HCV being thought of as an STD (which it is not). It was a great relief to find that neither my husband of 16 years nor any past partners had been infected.
58. It is very difficult to measure the impact of the infection on my education because I have always been infected. I have no idea how I might have been as a person without this infection. I was always nervous, anxious and found speaking in large groups very difficult. I was dyslexic and suffered with brain fog. These difficulties led me to choose a more artistic rather than academic path and I went to art college to study fashion and costume. I felt safer in this type of environment. I was unable to express myself in words but could achieve this through creativity. In this respect I feel I lost out: I may have done better academically if I had never been infected but I will never know.
59. The work related effects of the infection have been very great. I trained in theatre costume and started dressmaking after finishing college in 2001. I

experienced being very 'up and down' during my working life. On a good day I could work 12 hours a day, and on a bad day I just needed to sleep and suffered from anxiety and nervousness working with groups of people. I set up my own business working alone to enable me to work flexibly around these issues: I can take days off when I need to and can avoid being around groups of people. Given I am self-employed, the impact of the virus and treatment on me has meant I have struggled to return to work. This has made me feel very low. During the first course of treatment with Interferon and Ribavirin I could not afford not to work. I am a wedding dress maker and could not let anyone down who was already booked in. Although I managed to complete the dresses I did not have the will or the energy to continue to work on any other part of the business, like promoting the business, social media, website maintenance, etc, in order to keep the business going.

60. Since the trauma of the diagnosis, the two rounds of treatment, clearing the virus and the work I have had to do on my emotional health through counselling and my physical health through exercise, my business of the last 20 years which I built up on my own has pretty much ended. I was good at my job and really enjoyed it but now, even though cured, I struggle so much with concentration, admin, paperwork and the computer side of it that it fell apart. I used to be really efficient at running my business, and running my own website, admin, client communications, etc, but it has all slowly ended since diagnosis and treatment.
61. Financially, HCV has had a huge detrimental effect on my business which has been hit hard as I have neglected what was a very successful business for nearly 20 years. As a self-employed person I receive no benefits or sick pay. As well as losing a significant amount of income from the effect the virus and treatment has had on my business, I have also paid privately for a personal trainer during treatment to help rebuild my body and my strength, nutritional help to try to mitigate the effects the drug regime has on your insides, and on private counselling to try to come to terms with it all.

Section 6. Treatment/Care/Support

62. I was never offered any counselling or psychological support in consequence of being infected. I asked my hepatitis nurse for help after treatment ended as I was struggling mentally with things. But after treatment has finished they see you as 'cured' and they tick you off their list. I was told there were no funds for counselling. I have subsequently been sent information from the EIBSS with options for requesting financial help to cover various things, one of which is counselling. I am going to apply for this now, but I do not recall ever seeing this as an option before.
63. I needed psychological and emotional support from the start and would have found this very beneficial. During the adoption process I contacted Bedfordshire Wellbeing Services for help with my emotional wellbeing. I was put on a six month waiting list but, as I needed help straightaway, I found a private counsellor. This is the only reason I am able to sit down and write this statement for the Inquiry: until now I have been unable to talk about this. The counselling has saved my life.
64. The counselling has enabled me to talk about what has happened to me without crying, which was a concern for social services in the adoption process. As part of this process, and to help myself in coming to terms with what has happened, I have gone back to Dr GRO-D to tell him how I feel, including asking why he never took me seriously when I described my symptoms at many appointments over the years. Dr GRO-D response was that he had no idea and he was very sorry. This has helped me to understand that his dismissal of me was not personal, even though that is how it felt over the years. I am coming to understand that it is not so much individuals, but the system, which is to blame. However, I have first hand experience of what it is like to be treated as a young (now older) female, who has been overweight at points, and how, when this is the case, this is the only thing that medical professionals see: the weight is seen as causing the problems, rather than the

other way round. I do believe that this treatment is based on my sex, as my husband has never experienced anything like this. My emotional reaction to questions regarding my weight, which was the only issue GPs were ever concerned about, was another reason for seeking counselling.

65. I was born with HCV and, until I cleared the virus, have never lived without it. I have no point of reference as to how it feels not to have it, or how an illness feels like without it. For the first two years after clearing the virus I panicked every time I felt a bit of a sore throat or a cold, in case the virus had returned. It sounds crazy, but I have known nothing else and when I had a cold in the past I would be sick for months. I am gradually getting used to the idea that if I get a cold the virus may not have come back. I know that my body is now stronger and fitter. I haven't had a real cold or illness for approximately two years as I have spent the years since I cleared the virus focussing on getting my body as healthy as possible. My BMI is still high and I still get judged for it, particularly within the adoption process, but I now do boxing and weightlifting and am strong, if heavy. After six months of therapy I am no longer so concerned about what others think of my BMI, I am good enough.

Section 7. Financial Assistance

66. The NHS did not give me any information about the financial assistance available. I only found out about the Skipton Fund, now the EIBSS, through my mum, as she had received an ex gratia payment in around 1991. She only knew of the Fund's existence as someone at her work had heard about it.
67. Once I had been diagnosed I informed the Skipton Fund via their website after supplying them with medical confirmation of the HCV and the genotype, which was the same as my mum's. I received the same lump sum my mum had, £20,000, and, even though the payments were 20 years apart there was no increase to account for inflation. I also receive around £500 per year fuel allowance and, after filling in lengthy forms, £250 per month. This sum is

based on joint income, which I do not feel should be the case as a partner's income should not affect my individual payment, and it takes away any independence I have as a person.

68. When I was on treatment I requested further financial support because I was losing money as a self-employed person and paying someone to take my place when I was too ill to work. My request was refused after filling out lengthy and complicated forms and the refusal was again based on combined income. I do not believe my husband should have to bear the burden of supporting me financially during an illness and treatment for something caused by the government and the NHS. If I had not had his financial support I would have lost my business and become homeless. Eventually I was granted £750 per month for the duration of the treatment and a further £750 for post treatment respite care.
69. Last year, 2017/18, my monthly payments were increased to £1,500 per month which has greatly helped because I have been able to take time off work to rehabilitate my body and mind. I now accept that my business has come to an end, for the reasons described above, and I am dependent on my income from the EIBSS. Though I am grateful for this, it is scary, because that income hangs in the balance and could be taken away at any point. I would much rather be in control of my own finances and my own destiny.
70. Every time I have applied for financial support I have had to complete lengthy forms which feel like begging letters. When applying for a grant to cover a particular item I have to provide three quotes in support. The way the payment schemes operate have made me financially dependent on my husband, and this should not be the case.
71. I think £20,000 can sound like a lot of money but when you consider that a professional job pays around £30,000 a year, and you lose many working years to this virus, then it barely scratches the surface. This sum is less than if

I had had HIV, or HCV causing liver cancer, which is when the payment reaches £50,000.

Section 8. Other Issues

72. The fall out from the contaminated blood scandal is massive and there has been no attempt made to stem it, to this day. There has been no concerted effort to stop the spread of this virus. The secretive and cowardly way in which successive governments have swept this under the carpet is unforgiveable. The only way to make amends is to admit what has happened, to finally put out a campaign to get people tested, and to stop blaming sex, drugs, tattoos and anything else they can.

73. I want the government and the NHS to take full and complete responsibility for the contaminated blood scandal; I want the continued spread of this virus to be stopped as soon as possible; I want treatment for those who ask for it, without begging; and I want financial help for those infected.

74. I want those responsible for the scandal to understand how it has affected people's lives, in real terms, over decades of suffering silently, whilst being made to feel foolish and ashamed for being infected by contaminated blood.

Statement of Truth

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

Signed GRO-C

Dated7 August 2019.....