

Witness Name: Jennifer Parker

Statement No.: WITN4230001

Exhibits: **WITN4230002-13**

Dated: 06.2.21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JENNIFER PARKER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 October 2020.

I, Jennifer Parker, will say as follows: -

Section 1. Introduction

1. My name is Jennifer Parker. My date of birth is GRO-C1963. My address is known to the Inquiry. I have lived in the area for 55 years. I am married. My husband's name is Stephen. I retired 10 years ago. Previously, I was a teacher. I intend to speak about my infection with Hepatitis C (Hep C). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on myself, my family and our lives together.

2. I can confirm that I am not legally represented. The anonymity process has been explained to me and I am happy for my story to be in the public domain.

Section 2. How Infected

3. I believe that I was infected with Hepatitis C during the birth of my daughter whom of which I had by caesarean section. In around December/January 1988/9, at my 16-week check-up at Lancaster Royal Infirmary, I was required to undergo various blood tests. This was a surprise because Katy was my first child and I didn't know what to expect. I was asked about family congenital disorders. One of the tests they wanted to perform was for Hepatitis C. I specifically remember this because I had never heard of it. I remember the nurse mentioning it was 'one of these nasty diseases from the USA' but she also assured me that it was routine. I was just worried about HIV which was very prevalent at the time. I didn't see the doctor, nor did I receive the results.
4. Four weeks prior to the birth I was admitted into Lancaster Royal Infirmary where it was explained that amniotic fluid was seeping out of the womb. I developed a bacterial infection and was pre-scanned for a caesarean. Two pints of blood were cross-matched. This is exhibited at Exhibit **WITN4230002**. I am not sure whether this was a routine procedure at the time. I was reluctant to undergo the operation after everything that I had read in the news about AIDS but I had little choice

due to the potential risk to my baby. My daughter was born on GRO-C 1989 by emergency caesarean. This is exhibited at Exhibit **WITN4230003**. A letter from my medical records notes a 700ml blood loss. This is exhibited at Exhibit **WITN4230004**.

5. I am certain I was given a blood transfusion, which is the only blood transfusion I have ever received. Dr Healy, the hepatologist overseeing my treatment for Hep C in 2003/2004 at Airedale hospital contends that this is the most likely cause of my infection. To support my assertion, I draw attention to the remark made in Exhibit **WITN4230003** where Dr Stepanek mentions; "...her haemoglobin level was only 9.8 g/dl for which she was commenced" where I believe she means given a blood transfusion.
6. When I awoke, Katy's dad was there. I was still in the recovery room before going into the ward. I can remember saying that I was in so much pain. I was in agony – but also panicking because I wanted to know if I had been given any blood. My ex-husband knew how worried I was. One of the nurses noted on my records that I was 'not keen on having a caesarean'. This is exhibited at Exhibit **WITN4230005**. When I asked the nurse, her words were 'you've just had a little bit because you were bleeding'. I thought how a 'little bit' doesn't make any difference. It's in my system. It was never mentioned to me at any stage, even when the caesarean was discussed that I might need a transfusion.

7. If I recall correctly, I was discharged on 29 or 30 April and Katy was discharged on 14 May. She was kept in hospital for about four weeks after her premature birth. I was home during this time. About six to eight weeks after the birth of my daughter, one of the older doctors from Meadowside Surgery, Lancaster visited my home for a check-up. I can remember him bursting through the door and saying, 'I just want to tell you, you don't have HIV'. I was a bit aghast as these were the results from the tests I suspect were performed at 16 weeks, long before I went into hospital and this was the first I had heard of the results. I think perhaps I had put it all to the back of my mind.
8. Towards the end of the 90s', after my husband and I separated, I moved into a shared house with Katy and four other women. I went to university and afterwards moved abroad to teach English as a foreign language. I joined my now husband Steve in Belgium because he was working there on the new telecoms network. Steve and I returned from Belgium in around 2002/2003.
9. At some stage GRO-A came around and asked how I was. She knew I had been feeling a bit under the weather, so to speak. I told her that it was hard work decorating the ceilings and that I just didn't feel as well as I used to. She told me that her husband was really ill after being diagnosed with Hep C. She asked if I had heard of it and told me that it was linked to drug use and blood transfusions. She suggested that I might have contracted it after the

transfusion I had when giving birth to Katy and advised me to get tested.

10. I have not had a transfusion since nor have I ever used IV drugs. I was happily married at the time and not sexually promiscuous. I had my belly button pierced in I think, 1999 but it was carried out at a professional studio. I had an abortion in October 1993 but did not receive any blood products during the procedure. In 2001, I underwent a colonoscopy for cervical cancer in a private hospital Belgium. This did not involve any blood transfusions. It was a removal and I wasn't hooked up to anything.

11. In May 2003, I made an appointment with my GP, Dr McKirdy at Bentham medical practise. I requested a Hep C test. The doctor laughed and assured me that I would be alright. I was out celebrating my 40th birthday and my mums 70th birthday when I received a phone call from Dr McKirdy to inform me that I had Hepatitis C. I could tell by the tone of her voice that something was awry. I was in the car and trying not to let Katy or my mum hear the call.

12. It was not an opportune moment to hear of my diagnosis but then I would have rather known sooner than later. If she had asked me to go to the surgery, I would have known that something was wrong anyway. It would have been a shock in any circumstances.

13. Dr McKirdy arranged for an appointment face-to-face. She has a very nice doctor's manner and sought to reassure me. She probably said something along the lines of 'we need to come up with a plan'. She explained that I would have to see a hepatologist. She was very good at explaining things although she admitted that she didn't know anything about the virus. She provided me with a printout from the internet and then of course I went mad trying to find as much information as I could. She asked me if I wanted to go to Lancaster Royal Infirmary or Airedale. I knew too many people at Lancaster Royal Infirmary and in the town and did not wish to explain that I had HCV to anyone and so decided to go to Airedale.

Section 3. Other Infections

14. I was tested for both HIV and Hepatitis B when my daughter was being born which were negative. I am not aware that I have suffered any from other infections but I have experienced a number of other medical conditions which to my mind are a direct result of, or have been exacerbated by, exposure to the Hep C virus.

15. I do not recall being told of any risk in relation to vCJD.

Section 4. Consent

16. I consented to all the blood tests that I've received. I consented to the treatment and the blood tests that I received in relation to this infection.

17. As previously iterated, I did not consent to the transfusion I received in relation to the caesarean.

Section 5. Impact

18. Having Hepatitis C has had a huge impact on me. Learning of my diagnosis was a bombshell. I almost felt like, 'I told you so'. I was angry because I never wanted a caesarean for this very reason; I knew how dangerous it was. I have always felt unlucky. My sister was killed in front of me when I was seven in a farming accident. I can recall it vividly – one of the few memories that I do still recall from my childhood and formative years, the rest of which are blanked out. My mum was also hospitalised in my presence for six months, having been knocked down by a car. I was only 10 years old at the time

19. In the mid-late 1990s, I began to feel unusually fatigued and achy. I had always done a lot of running but began to feel abnormally tired. When I was decorating my house in 2003, I particularly noticed the weakness in my arms; I couldn't build up muscle. I was continually feeling exhausted going up and down the ladder but just attributed it to age catching up even though I wasn't particularly old.

20. I suffered from depression and huge mood swings for which I was prescribed Prozac which I had been taking intermittently since the mid 1990s' until 2010. This was not something that had ever affected me in

the past. I weaned myself from the drug as I was worried about addiction.

21. I moved to Italy in July 1999 to teach English. During that period, I noticed that my hair was falling out. I recall I returned to Lancaster for somebody's wedding and it was coming out in handfuls and filling the plug hole of the shower. I was concerned but didn't see a doctor. Unless things were really bad, I attributed it to hormones or something like that.

22. In 2002/2003, having returned home I worked for an estate agent in Lancaster. At times, when I was showing people houses, I couldn't remember which keys belonged to which house or who I was showing around. I used to get really agitated by this. It was embarrassing and affected my confidence and ability to fulfil my role. I told my husband who advised me to leave my job. It was only when the problems with my memory worsened in 2008/2009 that I realised it was 'brain fog'. It has since been an ongoing problem.

23. In my younger days I used to go fell running, climbing and swimming. I kept this up until I did a fun run in Blackpool. It was only 10k and yet my ankles became swollen. I required crutches. I didn't really know why because I ran quite frequently. Since then, I have been unable to run again. I tried to take it up again seven or eight years ago because the ankle joint pain appeared to have subsided. But, instead of getting fitter, I found the joint pain returned and I became more feeble.

24. I have since been diagnosed with fibromyalgia which debilitates the joints. My knees, ankles, spine, shoulders and hips are all affected. This seems to be becoming worse. Even as I am sitting here, I have pain in my joints. The muscles in my arms are tender and my rib cage hurts. I don't know how many mattresses Steve and I get through trying to alleviate my aches and pains. I can recall being in third year at university 1997 and my legs seizing up and becoming stuck. I would have to physically lift my leg up. This is now a constant occurrence. I also believe I have had arthritis since the 1990s.
25. In 1991/1992, I developed a rash alongside several lumps on my legs which were really painful to touch. I also had flu like symptoms and felt really poorly. I was off work for a few weeks. It was very debilitating. The doctor diagnosed me with sarcoidosis. He was delighted because the condition was really rare and he had not yet been confronted with it in his career. I realised later on that it can impact one's internal organs.
26. There are several other problems which I can list; I have had constant dental problems that started after Katy was born. I have undergone numerous x-rays to try and discover the problem but now have a mouth full of fillings where previously I had few. And it is ongoing. 3 years ago, I was diagnosed with an immune condition that weakens the skin within my mouth. It is called Lichen Plannus and is apparently a common side effect of HCV infection.

27. Another immune deficiency condition I suffer from is Lichen Sclerosus, an inflammatory skin disease that particularly affects my genital area. I have had it since the late 1990s or early 2000s but it was only diagnosed in 2006. It can be treated but not cured.

28. I feel that I should also mention that since around 1994/5 I have become susceptible to migraine headaches. These can be extremely debilitating. At first, they were not too frequent but over the years they have become an ever-present to the extent that they are simply now a fact of life. They can be triggered by bright light or sunshine and often I have no alternative but to lie down in a darkened room until the headache passes. That used to be 20 minutes but now the time is much greater.

29. I did not experience any of these problems prior to the birth of my daughter and to my mind, many are related to my HCV infection. Whilst I realise that some will come with age, surely not all and not to the extent that my body has been ravaged in that time?

30. I believe that the Hepatitis C infection also triggered an early menopause, the first signs of which were in 1994/1995. After the treatment, I had a blood test in 2006 and was told that I was post-menopausal.

31. After my diagnosis, I felt alone. I didn't know anybody who had it. I felt like HIV and Hep C were lumped together from a stigma perspective

and was therefore reluctant to share my diagnosis with anyone. I was referred for a private consultation with the hepatologist, Dr Healy which took place at Airedale Hospital. He admitted that little was known about the virus but was very reassuring and expressed his belief that the likely source was the transfusion I had received. He ran further blood tests to confirm that I had the virus.

32. I was genotyped to decide which treatment to provide. A letter from Dr Healy on 10 October 2003 confirms the virus and that I was genotype 3a. See Exhibit **WITN4230006**. Dr Healy also arranged for a liver biopsy which revealed low to moderate damage. I was referred for treatment. This is exhibited at Exhibit **WITN4230007**. I do not know the current condition of my liver. I was told to avoid alcohol. The liver biopsy was extremely painful and to an extent this is the reason I have avoided further liver examination as it is not something I would wish to repeat. Maybe I was being overly sensitive but I recall the nurses involved looking at my notes, commenting on the Hepatitis C and looking at each other. That knowing look. They put their gloves on and didn't say a word to me. The whole episode was a bad experience and I felt very alone and judged.

33. Around two months after my consultation, in March 2004, I began a six-month course of combined therapy; ribavirin and interferon. They injected me and kept me in the ward overnight so that they could monitor my condition and reaction. Dr Healy arranged a follow-up appointment in three months' time.

34. I was discharged with the treatment. After around six weeks, I started to feel very unwell. I remember having to inject myself in the leg with the interferon. I didn't like having to do it. My current husband asked if he should do it as I was really squeamish. The ribavirin was in tablet form.

35. After my diagnosis, in November 2003, I bought a horse to distract myself. However, during the treatment I was experiencing extreme fatigue to the point where I would come home and collapse – I had started work in a nearby supermarket to pay for the horse. I couldn't look after it and that responsibility eventually fell to my mother and Steve. My condition deteriorated to the extent where I didn't know what was going on. I would be watching the TV but couldn't tell what they were saying. I was totally blank.

36. I went to my appointed check-up, told them what was happening and had blood taken. Two weeks later, I was out and Steve got a call from Dr Healy urging him to take me to the surgery to collect a prescription for beta blockers because I was very ill. Apparently, I had to have them immediately. When Steve came to find me, I had been lying down in the middle of a field. I knew it was weird but I just needed to go to sleep. I came around and knew I needed to get up and I managed to get back to the road. I was walking very slowly, in a daze when Steve found me, lifted me into the truck and took me to the surgery.

37. Dr Healy decided to discontinue the treatment after only 3 months as I recall, because I was so poorly. He never really explained why I needed the beta-blockers but simultaneously they had picked up, he said, that it could be the result of my medication. Tests also showed my thyroid had been knocked out and I was having a 'thyroid storm'. I was later diagnosed with an overactive thyroid at Airedale, for which I was prescribed thyroxin which I still take today. I think I stopped taking the beta-blockers when I started on the thyroxin. I believe that he thought the treatment may also have triggered this condition. That is certainly my opinion.

38. I never returned to treatment for my HCV. The problem with my thyroid took precedence due to its serious nature. I recall Dr Healy telling me that the 3 months I had been on the medication may be sufficient in any case. Sure enough, after what I believe was a couple of further visits to see him, on 30 August 2005, Dr Healy gave me the all clear. This is exhibited at Exhibit **WITN4230008**. It felt fantastic but it was also difficult to accept as the virus is intangible. You cannot see it and it is not something everyone knows or talks about. You live with the knowledge the residue is always there. I continued to visit the hospital for up to a year afterwards in order for my condition to be monitored.

39. Having HCV has impacted my dental treatment. In 2003 when I returned to Lancaster, I arranged an appointment with a dentist in Settle. I provided my details including that I had been treated for Hep C. I was questioned about my HCV and initially was told there was no

space available but I believe at some stage they did treat me. During the appointment, the practitioners wore masks, gowns and gloves. It was a very negative experience and I never returned. They made me feel dirty. I think because Hep C is blood borne and associated with STIs, it is considered inherently dirty. I knew this was what people were thinking. I eventually got treatment a few years after on Brock Street in Lancaster with no issues but you would think that by 2003 any medical professionals would be aware of what the risk was and would be able to put you at ease whilst treating you safely.

40. I continued to work for the first few weeks of treatment. I had informed my manager that I might start to feel unwell. I had to have two or three weeks of sick leave. My manager was worried and thought I had cancer. I never let on what it was. I just couldn't even though she was quite understanding.

41. Even when I had cleared the virus, I was told that I still had markers. I couldn't accept that the virus was no longer transmissible. I was always worried that there was some way I could pass it on and this was the case for some time.

42. My family were all lovely. They were just shocked for me when diagnosed and full of concern for my well-being during the treatment and its side effects.

43. My dad was devastated when he learnt of my diagnosis. He was so downcast. He is very up-to-date on the news, especially with regards to anything medical. When I told him that I had been given blood, he said he knew straightaway this would have been the source.

44. My mum was experiencing the onset of dementia when I was diagnosed. I wasn't aware of this at the time. When I told her that I might die – and I did think this. I associated the virus with HIV which I was aware could be fatal - and that I was worried, she just shrugged and said 'I know what you mean'. She didn't really understand. I remember being a bit annoyed with her. I suppose that was an indicator that she wasn't very well. After that, I didn't want to tell her anything that would cause her any stress and be detrimental to her mental health.

45. Katy was about 13 at the time of my treatment and desperately worried. She tells me now that she thought I was going to die. I feel guilty in retrospect because I don't think I realised the extent to which my diagnosis affected her education. I had told her this momentous piece of information and then had no control over how she would process it; Her mother who should be her rock had suddenly become fragile. Consequently, she became very insular, noncommunicative and always seemed worried and withdrawn. It took her a long time to come to terms with my illness. Even in her twenties she didn't talk about it.

46. [GRO-C] I had to contact [GRO-C] and this was strenuous as our relationship is not great. He was annoyed to say the least. [GRO-C] [GRO-C] I would have been devastated if my illness had impacted on him. Furthermore, [GRO-C] [GRO-C] needed to be contacted. He wasn't very kind during our time together but all the same I felt I had a duty because this illness has had such a significant impact on me and he would likely have a new partner. I was even worried about my parents as I had lived in their house and used their bath. I was paranoid about the possibility that I had given it to anybody. It was my conscience that said they needed to get tested.

47. I was also worried that I might transmit the virus to Steve through intercourse. Both he and Dr Healy reassured me but I always found it difficult to shake the concern. That I had not given it to my former husband testifies to the fact that it would be unlikely to transmit but even that did little to allay my fears. I didn't want to be responsible for passing it to someone else.

48. I feel fortunate that I was married. I think if I was single, it would have been an absolute nightmare.

49. Prior to treatment, I was worried about drinking out of glasses at friends' houses. When I told my long-term friends, although generally supportive I got the impression that some thought I'd made too much of it. However, one of my friends whom I had been very close with since I

was 18 seemed judgemental and disapproving. I felt as if she now didn't trust me and distanced herself somewhat from my company.

50. It took me a while to feel comfortable to even have spa treatments.

When I finally went, it was a moment of acceptance that I was not going to transmit the virus to anybody. I had carried that anxiety for 10 years.

51. After the treatment, I found I couldn't cope with the family things that were going on. My husband's niece was dying of cancer. My mum and dad moved in next door. My mum had dementia. She and my dad needed my help. There was so much going on, I couldn't deal with the stress and strain of it at all. It was an emotional consequence of what I had been through. The effects of the virus - and the treatment on both my body, but particularly my mind, over the years. There is a tinge of guilt that I wasn't able to provide the help they required.

52. I remember I really lost my rag with my dad on Christmas day in 2003. I got angry with him for moaning. That was out of character for me. I believe this was a result of the mood swings caused by the Hep C.

53. I think the brain fog affected my career. In 2003, I wanted to return to teaching. I completed a 10-week refresher course and began applying for jobs. But as my memory, anxiety and consequently confidence difficulties progressed, I realised I would be unable to cope with such responsibilities. I would have liked to have pursued this for longer but the brain fog was debilitating. There was no way that I could continue

with it. In the end I took a less challenging option and worked at a local supermarket.

54. In 2010 I retired. My anxiety had developed to the extent that I couldn't retain information. I couldn't hold things in my head. I would walk into a room to speak to someone and by the time I had left, I had completely forgotten what they had mentioned. This was not conducive to holding down any sort of employment. I believe this was caused by the Hep C and resultant treatment.

55. Career wise I didn't really get to fulfil my dream of teaching again and this had a subsequent financial impact as the earnings in that sphere of employment would have been far greater than what I realised in the role I eventually took up.

56. During treatment, my husband was working in Scotland. He was worried about being away from me, especially during treatment as he knew I didn't like injecting and he was aware of how I was affected by the medication. He was really good. He took time off from his career whilst I was undergoing treatment and also to accompany me to my consultations with Mr Healy.

Section 6. Treatment/Care/Support

57. I think the Hospital overseeing my care did the best that they could have done for me at the time. I felt in very good hands with Mr Healy.

58. Every time I went to the doctors after my diagnosis, if it was anything to do with injections, I would inform them of my Hepatitis C status. I tried to be open about it and explain my circumstances because this is precisely how I was not treated. Practitioners were always really inquisitive. I felt that people would think I was a drug user and that although they may agree that I had acquired it through contaminated blood, that they would harbour a suspicion to the contrary.

59. I have never been offered any counselling or psychological support either at the time of my diagnosis or during the treatment stage. This is despite my treatment for depression, which I am aware is a symptom of HCV and its treatment but for which I have only ever been offered prescription medicines.

Section 7. Financial Assistance

60. I have never received any support from any fund or scheme.

61. If I recall correctly, I was referred to Skipton by either my GP, Dr McKirdy or my dad. The availability of financial support was not mentioned during my diagnosis or in the course of treatment at Airedale. It was not mentioned until I received a letter. I do not know who this was from. I was unsure whether I wanted to apply as I was initially worried about taking money from the NHS although my father assured me that it is sourced from a separate fund. Also, anything to

do with the Hep C is not necessarily something I wanted to bring up again.

62. I believe after receiving a second letter from them, I eventually applied to the Skipton Fund in September 2010. This is exhibited at Exhibit **WITN4230009**.

63. The following month, they wrote back saying that I was not eligible because there was not any proof of a blood transfusion and they mentioned [GRO-C] This is exhibited at Exhibit **WITN4230010**. I know I had a blood transfusion when I had a caesarean yet how can I prove this if there is no record?

64. I had already applied to access my medical records from Lancaster hospital. The medical records in Royal Lancaster Infirmary were in absolute turmoil. I have a friend, who at the time was a secretary there and said that all the old files were scattered everywhere. It was chaos. This has been ongoing for at least 20 years. When I did eventually access my files, I noticed that there weren't any records from [GRO-C] [GRO-C] 1989 when my daughter was born until [GRO-C] when she was discharged. I had thought this date to be earlier. I feel I have been penalised for the fact that records have been destroyed or mislaid by the Health Authority.

65. On 2 November 2010 I appealed. See Exhibit **WITN4230011**. I wrote to Skipton on 27 January 2011 with further information to bolster my

appeal. In particular, I had confirmed that my ex-husband did not have Hep C and that a blood loss had been recorded during the birth of my daughter. This is exhibited at Exhibit **WITN4230012**. Whilst I was now aware that [GRO-C], I was unaware of this back then, as it was at a time when he was conducting an affair behind my back. When I got in touch with him, he told me that he had never been infected with Hepatitis C. I passed this on to Skipton.

66. My appeal was rejected on 10 May 2011 again on the basis that there was no proof of transfusion. This is exhibited at **Exhibit WITN4230013**. They did not mention [GRO-C] on this occasion which suggests that they accepted my contention that [GRO-C] did not have the virus and therefore this was not a likely source of my infection.

67. I would have to think carefully before I would go through the process of applying to EIBSS because I know they will require that crucial bit of information that I had a blood transfusion and I worry it would feel like I was bashing my head against a brick wall. It seems the criteria for an award sets you up to fail.

Section 8. Other Issues

68. Having watched documentaries about the infected blood scandal, there appeared to be an air of arrogance within the blood transfusion service. They were informed in the early 80s' by America and parts of Europe that blood was contaminated yet they did not act accordingly. Most

European countries had started checking the blood years before the UK. I just wish that we had done the same. I feel resentful that whoever was in charge thought they knew better to interfere with people's lives. I have always been very socialist and support a heavy taxation system so an NHS is funded in order that people can access the treatment that they need. Yet, this is my only hang-up with the NHS that they have allowed this to happen. It makes me feel more bitter to know that had the UK just listened to other countries, this could have been avoided.

69. Interestingly, I attended Blackpool Infirmary around 4 years back where I had an angiogram, due to experiencing an abnormal heart rhythm. The consultant who dealt with me there went on to mention that I should perhaps follow up on my treatment for my Hepatitis. He did not expand. This made me think; what does he know that I don't. Is there an ongoing problem? I do tend to bury my head in the sand but this is something that I will now follow up on.

Statement of Truth

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

Signed

GRO-C

Dated

10th Feb 2021