Witness Name: Karen Pearce
Statement No.: WITN0235001
Exhibits: WITN0235002/006.
Dated: 13th March 2019.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KAREN PEARCE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26 October 2018.

I, KAREN MARY PEARCE, will say as follows: -

Section 1. Introduction

1. My name is Karen Pearce, I was born on GRO-C 1956 and my address is known to the Inquiry. I am not legally represented at this time and I am happy to give this statement to the inquiry.

2. I received contaminated blood and caught a virus during a blood transfusion. It took a long time until I was diagnosed. Quite recently I have had treatment for the Hepatitis C, and this has proven successful.

Section 2. How Infected

3. I was infected through blood transfusions. Reading my hospital notes was depressing, it read like a horror story. I had two sets of blood

transfusions during both of my pregnancies at the Maternity Ward 6, Good Hope hospital, Rectory road, Sutton Coldfield, B75-7RR, under the same consultant, Dr Crawford. I had a difficult labour with both children and both were born 4 weeks early.

4. The first set of blood transfusions were in 1976. During my pregnancy with my son David, I had problems with my kidneys. I had to have a nephrectomy, where I lost one kidney. Overall, this resulted in three blood transfusions. I had my first blood transfusion during the nephrectomy surgery, on [redacted] 1976; I was [redacted] weeks pregnant at the time. During this period, I didn't know if they could save my son but they did. I was proper poorly. The nephrectomy was performed by Mr Hurford.

5. I also had a second blood transfusion to treat my anaemia, but I don't have the date for this. I do remember how well I felt after receiving it and the iron transfusion. I used to walk round the ward helping the nurses with bed making and giving out drinks. I felt great. The third blood transfusion was during David's actual birth, on [redacted] 1976, it was given to me because I had lost a lot of blood. I had three blood transfusions in 1976.

6. The second set of blood transfusions, occurred during my pregnancy with my daughter, Julie, in 1989. On 8th February, I had two blood transfusions, they needed to give me three units of blood to treat my anaemia. My blood type is not that common, its rhesus-negative, so they were having difficulty finding compatible blood. They could only find two units in the whole country. I then had to have another blood transfusion on the 14th March, to treat my anaemia again.

7. I get really ill when I'm pregnant. With Julie, the GP sent me straight up to the hospital to see if I could continue with the pregnancy. During this period, I had to have a catheter inserted to improve the function of the remaining kidney and the doctors were considering a kidney

transplant. They had asked me if there was anyone who could donate a kidney from my family, but it all worked out ok.

8. Meanwhile, I contracted the parvo virus when I was 6 weeks pregnant with Julie. The parvo virus carries the same symptoms as rubella and the doctors were worried if it carried the same birth defects. I could have lost Julie. On top of all of this, Julie's father left me for another woman. This was a very worrying time for me.

9. I had the final blood transfusion on the GRO-C 1989. On that day, the consultant delivered the baby via caesarean and then immediately performed a second surgery, to sterilise me. I was blood transfused and I had no say in it. I can remember the actual transfusion. I remember seeing the bag with blood in it, on a stand by the side of the bed and I saw a tube coming from the bag going into my arm. I could see the blood going in.

10. The doctors said, having another baby would kill me, this was why they had sterilised me. Obviously, I had to look after the two that I already had; they are little miracles really. So I can understand the doctors were trying to help.

11. Mr Crawford had seen to me all the way through both pregnancies, he even came in early, to deliver my baby (Julie). I believe I was infected with contaminated blood after the blood transfusions in 1989 because I never felt the same again. My son says, that he had one mum before Julie was born and that after she was born, he had a totally different person. I thought I had four blood transfusions in 1989, but I can only find information about these three, so far.

12. I think it is also worth mentioning that I received several anti-D injections during both of the pregnancies. My understanding of anti-D injections, is that they are given to you to stop the babies' antibodies from fighting one another. Luckily my son is the same blood group as

me, but my daughter is a different type. I read up on the injections and I have found out that the contained a blood product.

13. I do not remember being told, by anyone, anything, about risks from being given blood transfusions, before I got them.

14. As far as I am aware, I have only been infected with Hepatitis C as a result of being given blood transfusions. I have been told by a Hepatology nurse, that I have genotype 1A, HCV. I know that this has been linked to America.

15. I have had treatment for Hepatitis C, but it took a long time to get diagnosed. My daughter was born GRO-C 1989 and after that I kept having to go to the doctors, I felt tired all of the time. They told me I had depression. I felt tired and because I kept going to the Drs I felt like a hypochondriac. Every time I went to a new doctor I felt full of hope, but no one believed me; I felt so ill and I knew that I was ill. That was so frustrating.

16. In November 2016, I put on loads of weight; my stomach blew up. My son said that he thought that something was wrong. I looked like a corpse; I thought to myself I have aged really suddenly. I went on a diet but I couldn't shift the weight.

17. In February 2017, I went to the doctors, where Dr Roberts examined my blotchy hands, the spider veins on my skin, my itchy palms and my stomach. She asked me if I was a heavy drinker and I said 'no.' During this appointment, she also organised blood tests to see if I had a virus or an auto-immune disease. She also ran a blood test for Hepatitis C and referred me to a liver specialist. Dr Roberts told me that I had liver disease. She recommended that I stop drinking and to eat healthily.

18. At the follow up appointment with Dr Roberts, we discussed my blood test results. The Hepatitis C test came back as positive. Dr Roberts

explained that it was necessary to do another Hepatitis C blood test, to rule out that the first result was not a false positive. She then ran a further blood test for HIV on 11th May 2017.

19. Dr Roberts explained that I had caught a virus and that 'I will let you know the answer of these tests.' But she never got back to me. I chased it up, because at that time I was itchy and when I scratched, my wounds would keep bleeding. I was a bit worried.

20. On the 5th July 2017, I rang the Chirk Surgery, I spoke to the receptionist who referred me to the nurse to interpret my blood test results. The nurse explained that a doctor had to speak to me about my results. Dr Elizabeth Thompson called me the next day (6th July 2017) and told me, over the telephone, that I had Hepatitis C and that she would print a leaflet off, for me to pick up from the surgery.

21. Dr Thompson said, she didn't know very much about it, but that the day before we spoke, she had attended a conference on Hepatitis C and that the good news was that its curable.

22. The leaflet that Dr Thompson printed off, contained very basic information; don't share toothbrushes or needles and eat healthy. At the bottom of the leaflet, it did give contact details of the Hepatitis C Trust. Nobody told me to get my children tested. I just told them to do it, because I was worried about them. GRO-A GRO-A. GRO-A GRO-A.

23. I was and I have never been promiscuous in my sexual behaviour. I have never taken drugs by injection and I do not have any tattoos or piercings, other than my ears when I was 11. I was asked these questions around the time of my diagnosis as well.

Section 3. Other Infections

24. I do not believe that I have received any infections, other than Hepatitis C, as a result of being given infected blood or blood products.

Section 4. Consent

25. I do not believe that I have ever been treated or tested without my knowledge. I always knew what the blood tests were for; they ran blood tests on my thyroid and for anaemia because of my tiredness. I honestly think that the doctors didn't have a clue about Hepatitis C until it all got out much later.

Section 5. Impact

26. The mental and physical effects of Hepatitis C that I experienced in the long term, were chronic fatigue, depression, pain and nausea. I just felt like I had the flu for years.

27. I sought medical help for the depression. I first started talking to my GP in 1993, when my daughter was 4. I had no energy and just wanted to sleep the whole time. My GP referred me to a psychiatrist. The physiatrist told me, I had either atypical depression or post-natal depression. They kept giving me different antidepressants which made me feel unwell. I ended up having 2 batches of electric shock treatment, which each consisted of 6 sessions, these were in Queen Elizabeth Hospital, Birmingham. I eventually stopped going because nothing was working, but the medical staff said 'I was unresponsive to treatment.'

28. As a result of this, the Dr's sent me to an endocrinologist, because they said it was not a psychiatric issue, I had been diagnosed with a benign pituitary tumour, but when I saw the endocrinologist, that specialist noted that my symptoms did not correspond to the effects of

the tumour. In the end, I found out that my problems were down to the Hepatitis C virus.

29. Eventually, I ended up moving to GRO-C and giving up on doctors in 1997. I started trying natural health treatments such as, exercise and diet. I still get depressed now, but I don't know why, because I don't have anything to be depressed about. My poor daughter suffered really. Some days I just couldn't get out of bed to play with her or take her to school. I was also having mood swings.

30. The mental effects of being diagnosed were shocking. The first feeling I felt, was relief; thank God there was something wrong with me and that I am not going to have to feel ill for the rest of my life. The second feeling I felt was anger and embarrassment because, once I found out, I felt dirty and I wouldn't go anywhere. I did shut myself away, but then I got over that. Finally, I felt the shock of it, you just feel sick, gutted. It's just a shock really that you have been carrying it around in your body for years.

31. As a result of my infection with Hepatitis C, my liver has become fibrous, but it has not qualified me for a stage 2 payment yet. I have also developed fibromyalgia where my body hurts all over, as well as the chronic fatigue I experience. I was also told that I developed a fatty liver as a result of the liver disease.

32. They started treatment as soon as they could, they didn't mess about. On the 1st August 2017, I saw a consultant liver specialist, Dr T Mathialahan, at Wrexham Maelor hospital. At the start of our meeting, he said, 'do you know why you are here?' I remember replying, 'I believe I am here because I have Hepatitis C due to the blood transfusion.' He then said that, 'I thought that we had found everyone.' He told me that there was a waiting list and that thirty people were in front of me, so it would be a while and that I would receive treatment after Christmas.

33. On the 4th September 2017, I had a fibro scan, with a hepatitis specialist nurse. She gave me the score there and then of the state of my liver, on the liver stiffness scale, I scored 10.5. She said I was stage 2, which frightened me but when I did my own internet research, I discovered I was not at that stage.

34. On the 18th September 2017, I had to go and meet a different nurse, a hepatology support nurse. He just asked me questions and spoke about treatment options and what would happen. He was the one that I got the most information from and he was quite chatty. He was worried because I only had one kidney. I was going to go on the treatment, Harvoni, but then Maviret had just got approval. They chose Maviret because it was kinder to kidneys and it was said to cure people quite quickly.

35. I started my treatment 14th November 2017 and completed it on 9th January 2018. I had to take three tables a day for 8 weeks. The Maviret tablets consisted of 100mg of glecaprevir and 40mg of pibrentasvir. It makes you feel very weak. The quilt on my bed, felt like lead. I also experienced a loss of appetite and headaches. After I finished the treatment, I felt a bit weird, very depressed, I couldn't eat or talk. I felt like I was catatonic, but then time passes. I was grateful that I didn't have interferon. I just feel I got quite lucky, because I got the treatment quickly.

36. As Mavret had just come out and they had never used this treatment before, the doctors wanted me to have blood tests, to monitor me. My first blood test showed that I had a 6,006,600 viral load. Four weeks into the treatment the viral load was down to 23 and at the end of the treatment, it showed 12.

37. I had another appointment in April 2018, where they explained that they were unsure if the tablets had cleared the virus. This is because I

was still showing a viral load. I told the nurse then that 'I wished I never took it because it made me feel depressed' and he said 'is that because you still have the virus?'

38. I then went back for another blood test in June 2018. Eventually on the 7th September 2018, I got the letter saying that I have successfully cleared the virus. Three months after the last blood test in June 2018, the hepatology nurse said on the phone that 'we will continue to monitor you, on a six-month basis.' I remember being worried and asking the nurse the question, 'am I going to get cirrhosis'? She also said that she would speak to the consultant and get back to me about getting a fibro scan, (I had my last one in August 2017) and that call was in September 2018.

39. I can't fault the doctors, as soon as they realised what was wrong with me I was treated. I am gradually feeling better. They say it takes a year to get over it, but the symptoms of pain in my wrists and fingers as well as the itching has got quite bad recently. Maybe that is something I have got to live with for the rest of my life.

40. When the fibromyalgia, flairs up my body hurts all over and that causes the 'scatiness' too. The Hepatitis C nurse did say they are still learning about it today, because it takes so long to start showing symptoms. But I am going to ask them to retest me, just to reassure myself.

41. My dentist has been fantastic. I had a dental appointment the same day I got a letter from the Doctor (24th January 2018), saying that they thought that the Hepatitis C virus was still active, my viral load, was less than 12. The dentist that saw me was a young girl, but I refused dental treatment because I felt embarrassed and did not want to be a risk. So I waited until I had the all clear before having dental treatment.

42. I have been asked whether being infected had an impact on any of the treatments I received, whether medical and/or dental. The answer to

that is no, because the time between, me finding out that I was infected and being cleared was only a year.

43. I am not with anyone at the moment. I used to have partners. I used to be a very outgoing person, now I just seem to have declined. I have just isolated myself over the years. The impact on my daughter was really quite sad when I was depressed in 1993. She was four and some days I couldn't get out of bed, so she just lay there with me. Some days I was unable to take her to school. She never left my side. She would drink water and eat dry bread and would practice her writing on the walls, this was on the bad days.

44. More recently, the impact of my infection still affects me. Julie's partners' mother, went over to visit them, in Australia, and she is the same age as me. I saw pictures of her on a bike and I just thought to myself, I wish I could have done that. But I know my limitations. If I go to the shop it will take me a few days to recover, even now after I have had the treatment. My son helps me about the house, with the garden and the shopping. You muddle through don't you.

45. I do wonder what my life could have been like without the infection. My friend and cousin have got their own businesses and I just feel like the failure of the family. Everything went wrong for me. I wonder what my life could have been like. I am just happy my kids never had my life.

46. At first, I didn't tell anyone about my diagnosis, but then I did so I just texted some family members. I texted the ones I was close to, but I didn't hear anything back from them.

47. When I go into get a blood test, my blood is labelled with a big bright orange sticker. This is very embarrassing it says 'blood, risk of contamination'. I always feel I have to explain myself to the nurses; how I caught it, because of the embarrassing stigma and association with drug addicts, and being promiscuous.

48. I flunked out of educational courses, because my memory is like a goldfish and I have delayed reactions. I used to forget what I was saying mid-sentence, my daughter would finish my sentences for me. In 2000 I was accepted at Bath Spa University to do humanities but I never finished my exams at college, because of the struggle to remember things. I sometimes feel like the Teletubbies, I have to go over and over it, until it registers.

49. I bought an educational course in December 2017, but I have only done one assignment. I am still trying to do the second one at the moment. I used to be a really big reader and I used to love reading but I haven't read a book for ages now. I can watch a programme three times until I realise that I have already watched it. I put all these cognitive problems down to having been infected with Hepatitis C.

50. The infection has also affected my work, because it affected my stamina. I used to be a full-time chef, where you have to be on the ball, but as my memory faded I had to take more menial jobs because I couldn't cope. It used to exhaust me. I had to start taking part-time work. I didn't like people seeing me like that. So, I chose back of house jobs where you could complete the jobs in your own time.

51. As I could only work part-time I was not earning as much. Before I was diagnosed, obviously, I did not receive money from the funds. I did own my own house when I was married, but it was in my husband's name. I never got a share of the house when we split up in 1981; David was 5. GRO-D .

52. Financially, I never had the chance to get going again. It's hard because you are earning less and then you have two children. I put all of my finances into taking care of them. It was difficult not being well enough to keep a well-paid job and trying to raise two children, alone.

Section 6. Treatment/Care/Support

53. I have not faced any difficulties or obstacles in obtaining treatment, care and support since I have been infected with Hepatitis C.

54. I have not been offered any counselling. When Dr Thompson, confirmed my diagnosis, she did not offer me any counselling or psychological support, but I believe that if I want it, I can access it regardless.

Section 7. Financial Assistance

55. When I went to see the consultant, Dr T Mathialahan, on the 1st of August – he told me about the Skipton fund. He helped me get my notes together to prove that I had blood transfusions. At the time, Skipton, was just closing, but I they paid me £20,000 at the end of October 2017.

56. My GP thinks there's a link between depression and Hepatitis C and because of that I receive a payment of £1500 per month from the English Infected Blood Support Scheme, (EIBSS). I have been receiving this payment since September 2018. I receive uplifted payments, for chronic fatigue, fibromyalgia and depression. I got my doctor to go back over all of my notes, to fill in the forms and tick the required boxes.

57. On the 22nd August 2018, I began to receive income top-up payments of £4,344 per annum. These are given to me because of my low income. I also get a one off winter payment of £519. I have access to a repair grant if I need it, but I haven't had to call on that. In general, they keep you very well informed and they are really easy to talk to and get straight back to you. I feel I have been really lucky compared to a lot of people and the financial help has changed my life immensely. I don't have to count my pennies when I go to the supermarket anymore.

Section 8. Other Issues

58. I didn't realise that there was a recall for those who had blood transfusions, which meant that I could or should have been tested for Hepatitis C in the 1990's. I just thought, they had always been aware that I had had surgery. They should have been more informed and hands on. They should have thought that I had had a blood transfusion, so maybe we should check her for this. Why didn't they pick up on it? Why was I never involved in the recall of blood transfusions? I was still living in the same place and under the same hospital until 1997.

59. I have not taken part in any sort of campaigning or litigation in regards to infected blood matters.

60. I have parts of my medical records and have supplied some of these to the Inquiry. These documents I believe, show the blood batch numbers that were given to me during my transfusions. I will exhibit these documents and I describe these exhibits as follows:

    WITN0235002- form detailing four compatible bottle numbers: 17784, 22909, 21700, 09544. The laboratory number is: 763291 and the specimen received date is: GRO-C/76.
    (I am not sure that I received this blood)

    WITN0235003- form detailing three compatible bottle numbers: 21700, 09544, 13153. The laboratory number is: 763348 and the specimen received date is: GRO-C/76.

    WITN0235004- form relating to Karen Hagan (maiden name) two compatible bottle numbers: 10320, 10321. The laboratory number is: 763944 and the specimen received date is: GRO-C/76. There is a note under history, asking the question, 'previous transfusions, Yes/no.' The note reads, 'Yes- no reaction.'

WITN0235005- form relating to Karen Pearce, Hospital number: 187947, Ward 6, Good Hope Hospital. The medical officer is shown as Mr Crawford. The laboratory number: 9.7667.8 Location of compatible blood, compartment number: drawer 4A. The product code is: SAGM. The two compatible pack numbers are: 655743H0, 636804H2. Dates blood given for both of them is GRO-C/89. There are unreadable signatures against the blood being given.

WITN0235006- form relating to Karen Pearce. Hospital number: 187947. Medical officer: Mr W Crawford. Ward 6, Good Hope Hospital. The laboratory number: 9.8535.9 Location of compatible blood, compartment number: drawer 4A. The product code is: SAGM. The two compatible pack numbers are: 634998H6, 102335H7. Date blood given GRO-C/89. There are unreadable signatures against the blood being given.

Statement of Truth

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

Signed GRO-C

Dated 13. 03. 2019.