Witness Name: Marlene E. Neve
Statement No: WITN0936001
Exhibits: WITN0936002-005
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARLENE ELIZABETH NEVE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 01 May 2019.

I, Marlene Neve, will say as follows: -

Section 1. Introduction

1. My name is Marlene Elizabeth Neve. My date of birth is GRO-C 1954 and my address is known to the Inquiry. I am 64 years old, divorced and live alone. I have two adult children. Previously I was employed as a radiographer but I am currently self-employed as a foot health professional. I work from home up to 2 days a week.

2. I intend to speak about how I was infected with Hepatitis C, and Malaria, through a contaminated blood transfusion I received in 1987. In particular, I intend to speak about; the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my life.

Section 2. How Infected

3. In February of 1987 I was admitted to Burnley General Hospital to have a hysterectomy. I had severe menorrhagia causing me to be very anaemic over a long period of time. The operation was performed and I was returned to the ward where the usual post-operative observations were carried out. It became clear from the observations that I was haemorrhaging quite badly from the operation site, and emergency procedures were implemented.

4. I was given IV fluids, which were administered under pressure (manually squeezed) to try to elevate my blood pressure, I had oxygen, and the end of my bed was elevated. I was taken urgently back to theatre in order to find and repair the bleed.

5. When I regained consciousness I noticed, on top of the fluids, I was also being given a blood transfusion via a feed in my arm. Even then they could have used plasma expanders, but unfortunately they decided to use a blood transfusion. I was being administered with other IV fluids via my neck. My blood pressure had been so low, the only vein that could be used was one of the larger ones in my neck.

6. I was never told how many units I had been given. I stayed in hospital for the usual time, about a week, and I believe I healed well.

7. I have had no other blood transfusions, or been exposed to other opportunities of contracting Hepatitis C.

8. At the consultation prior to the hysterectomy I was working as a radiographer at the same hospital. We were aware of the rising issues surrounding HIV and I mentioned this concern to my consultant. I asked if I could donate my own blood in advance of the operation

should a transfusion be necessary. It was pointed out that I was not fit to do this, as my haemoglobin levels were too low to begin with, hence the need for the operation.

9. The consultant reassured me the need for a transfusion was probably negligible, and even if it did happen all the blood in our country was very well screened and our standards were high, I was told it was safe. At this stage HIV was my only concern, as I was aware that in the UK blood was not taken from high-risk individuals for transfusion purposes. Hepatitis C was not known about at this stage.

10. I am unsure of exactly when, but I think it was around 1989 when I was contacted by letter from either the Blood Transfusion Service, or Haematology department, to tell me that the blood I had been given had been infected with Hepatitis C. I was told I needed to make an appointment with my GP.

11. I saw my GP who said that I would be tested to see if I had actually been infected. The results came back they said it was a very unusual result and I was referred for further testing. They said I would have to have my blood tested regularly to keep an eye on things.

12. I am unsure when exactly, but I know it was sometime after I was informed of a possible contamination, when I was admitted to Manchester Royal Hospital for a liver biopsy. This in itself was a very painful and quite traumatic procedure because the doctor couldn't get the guide wire in place. Eventually the consultant took over and did it by eye; it was like being shot when the sample was taken.

13. I was given the results on the ward. They informed me I had been infected with Hepatitis C but unusually I had cleared the infection myself. I asked what that meant long term and was told that they really didn't know. There was no history to be guided by, the Hepatitis C strain having only recently been recognised.

14. The doctor advised me to act as though I had the infection i.e. use of condoms and informing anyone administering injections or medical care, such as dentists and medical practitioners so they could take the necessary precautions. I asked if my husband and children should be tested too, but the doctor said if they didn't have symptoms by now then they probably haven't contracted the virus. I was given a leaflet about the infection too. I was told they had no further information at that time.

15. I had the feeling that they wanted to play down the whole situation. I had cleared Hepatitis C, and because of that, they had an attitude of 'it was nothing to worry about'. They didn't even look into the malaria, almost like they wanted to brush past it, scared that it would open a whole other issue.

16. I was put on a mixed ward for the procedure, and I was given my results on a mixed ward. I felt uncomfortable and just wanted to get out as quickly as I could. I was kept under observation for a few years after, having regular blood tests. I was under the impression that there were not many people about like me. I had no idea of the scale of the contamination scandal.

Section 3. Other Infections

17. Whilst I was given the results of the Liver Biopsy I was asked when I had contracted malaria. I said I hadn't nor had I ever visited an area that could expose me to malaria. However, the biopsy had shown I had previous exposure to malaria.

18. I told the doctor that I had been quite ill earlier in the year with what was assumed to have been a virus. For 3 weeks I was very ill with severe headaches, I was fluctuating between burning up and sweating profusely, with severe chills and terrible shaking and vomiting. This

went on for 3 weeks and I was unwell for a long time after. When I explained these symptoms, the doctor said "yes that's malaria". I asked; "well where have I got that from?" He didn't answer as such, just sort of pulled a face and said "hmmm." I asked if it could have come from the transfusion and he said, "there was no other explanation and that it was a whole new can of worms."

19. I was subsequently diagnosed with Fibromyalgia. There is an increasing feeling that my exposure to Hepatitis C played a major factor in that. I often wonder if some of what I have assumed are fibromyalgia flares, have in fact, been due to the malaria as they have been increasingly milder versions of the original attack.

Section 4. Consent

20. I cannot be sure that I have not had any other testing or investigations without my consent. When I went for tests, or check ups there's often this air of "we're checking this that and the other, but it is just a precaution, and we're sure there's nothing to worry about." It was around 2007 when I was told the doctors would stop monitoring me; no clear explanation was given as to why.

21. I was contacted by a research programme based in Cambridge. The research group were looking into the small percentage of people who had cleared Hepatitis C naturally, in the hope of finding a successful treatment or preventative. Bloods were taken but then they seemed to disappear and they stopped replying to my communication. I cannot recall the name of the research group, but I have applied for a copy of my medical records, and this may provide an answer.

Section 5. Impact

22. This experience has been, and still is, quite harrowing. I had two young children at the time, and there was a dreadful worry of having

accidentally infected them before my diagnoses. Similarly with my husband.

23. There was worry that despite having cleared the infection the long-term situation was unknown. I was not sure if my life was going to be shortened; as a mother and the main breadwinner of the family the thought of leaving my family early, and in financial difficulty was a very scary prospect.

24. The thought of some sort of infected material flowing through my body, and parasites in my liver made my skin crawl. I know it was a useless exercise, but I cannot say how many times I have scrubbed my skin raw, in a hot bath because I felt unclean. I still feel that way today.

25. Sadly, my marriage ended in 2004 and once I felt ready to have a new relationship I had to have the conversation regarding the infection. Even though I cleared it. This has cost me 5 potentially good relationships as the other person, quite understandably, was not prepared to take what they saw as a risk. This saddens me, as I would love to have someone special in my life, but I have come to terms with the fact that this will now not happen. There are only so many times you can be turned away feeling like a piece of rotten flesh.

26. When going for medical checks and procedures I am always quick to point out that the Hepatitis C was as a result of a blood transfusion. Although nurses, doctors, dentists etc. are professional there is often a fleeting reaction which I feel assumes that I have lived a high-risk lifestyle, which isn't nice. I still feel there is a lack of education around Hepatitis C and this leads to stigma.

27. I have also been denied from donating blood as they won't take the risk, even though I am clear from Hepatitis C. No one can say if my organs could be used for transplant, which saddens me.

28. I have been diagnosed with Fibromyalgia, which immensely impacts, on my day-to-day life. There is no one in my family with any rheumatological condition. There are, however, many studies which conclude a link between Hepatitis C infection and Fibromyalgia. One of the questions asked by rheumatologists is whether I have been exposed to Hepatitis C.

29. Fibromyalgia and the symptoms I suffer consist of widespread body pain, headaches, memory problems, extreme sensitivity to heat and cold, crippling fatigue, IBS, sleep disturbances, intensely itchy skin, numbness of the extremities and more.

30. This has impacted massively on my ability to work, there are so many aspects to my condition that affect my work. After a short time my hands become numb, I have to pace bookings so that I can cope better. I have to pace myself throughout the day because after a short time I am in pain and become fatigued. My practice has gone from five and a half busy days a week, to between one and two. I often have to cancel and re book people as I quickly become too ill to work and have to go to bed.

31. My health also impacts on my social life. I used to like to go to the gym, but now I to consider whether I can physically cope with it, I rarely go out anymore.

32. I am in receipt of PIP at the higher level for both care and mobility. I am trying my best to maintain some dignity by trying to work one to two days until retirement age, which is just under two years.

33. I have no savings and I am very fortunate to have been awarded working tax credit and housing benefit, but I hate having to rely on the state.

34. There has not been a day gone by where I have not thought about my Hepatitis C status, and the true extent of what has happened.

Section 6. Treatment/Care/Support

35. I was not offered any treatment for my Hepatitis C, this was because I was told I had cleared the virus and did not need any. I was never given treatment for the malaria, and this was never mentioned again. I take a combination of medication for my Fibromyalgia.

36. Support has been in the form of leaflets and there has been no counselling offered. Looking back, counselling would have had some benefit. But for me personally, I needed information, real meaningful information. I have felt the whole process has lacked any transparency. I needed more than just a leaflet which underlined the little information I was already told.

Section 7. Financial Assistance

37. Other than PIP, working Tax credit and Housing benefit, I have not received, or been aware of any financial assistance from the available trusts and schemes.

Section 8. Other Issues

38. I requested my medical records a few weeks ago and upon receipt I noticed incomplete or missing files. There was nothing in relation to the first contact, by the hospital to myself, about the infected blood. There was nothing about the subsequent testing, biopsy, follow up or discharge. My transfusion was acknowledged in the hospital records, which I exhibit as (**WITN0936002 and WITN0936003).** These explain a transfusion was needed following a hysterectomy. However, the discharge letter to my GP, which I exhibit as (**WITN0936004**), mentions

nothing about the transfusion and describes the procedure as 'uneventful'. A subsequent medical record, which I exhibit as **(WITN0936005),** acknowledges contraction of Hepatitis C through transfusion.

39. I believe there needs to be training given to all medical professionals so they are aware there are people out there who have contracted these viruses, not just from drug use or sexual behaviour, but from contaminated blood given by the NHS. There needs to be a health campaign so the public at large are educated, through education the stigma can be dismantled.

Statement of Truth

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

Signed: **GRO-C**

Dated: 12/6/2019.