Witness Name: Jayne Young
Statement No.: WITN0948001
Exhibits: **WITN0948002-4**
Dated: 13th January 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JAYNE YOUNG

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 July 2019.

I, Jayne Young, will say as follows: -

Section 1. Introduction

1. My name is Jayne Young. My date of birth is GRO-C 1958 and my address is known to the Inquiry. I am a mother, a nan and a wife. I intend to speak about my experiences of becoming infected with Hepatitis C. In particular, the nature of my illness, how the illness affected me and my family, the treatment received and the impact it had on our lives together.

Section 2. How Infected

2. In 1988 I had an ectopic pregnancy. I was living in London at the time and I was bleeding heavily, blood was literally pumping out of me. I lost a lot of blood and was rushed to Basildon Hospital. I was prepared for

surgery and woke up with tubes in my arms and my mouth. I was completely out of it. They had cut me open and I had undergone a major operation.

3. I was in hospital for about two weeks in total, the first nil by mouth. I didn't know I was pregnant at the time of the operation, and it was only after the surgery that I realised I had lost a baby. I knew that I must have been given blood because of the amount of blood I had lost, but it was my partner at the time who told me that I was given a blood transfusion. My medical records show that I had undergone a laparoscopy, laparotomy and right salpingectomy. **(See Exhibit WITN0948002).** Unfortunately, there is nothing in writing in the limited records that remain to confirm the blood transfusion.

4. The risks of being exposed to infection through blood transfusion were not explained to me at any stage, nor did my ex-partner receive any such explanation that he subsequently relayed to me.

5. In July 2018, I went to the doctors to enquire about starting Hormone Replacement Therapy (HRT). I did some blood tests and the doctors realised there was something wrong with my liver. I was called into Wrexham Maelor Hospital to see a specialist. They got my husband and I in a room and told me that I had Hepatitis C. The doctor said "We are going to have to check your husband and daughter". I was in total shock. How could I have contracted something like this? This was something that I associated with drug use. I felt embarrassment as well as disbelief.

6. I don't drink or smoke, I have always lived a healthy lifestyle so I didn't understand how I had contracted it. I have never been an intravenous drug user and I am not sexually promiscuous nor have I any tattoos or piercings.

7. We went through my medical history to check where it came from. I told him I had an ectopic pregnancy in the 80s. He said "Bingo – that's it." I

asked him what he meant and he explained; "You were probably given contaminated blood, in the 80s blood wasn't tested, I think that's it." As far as I am aware that is the only time in my life that I had had a blood transfusion up until that point.

8. My husband and I were floored after that meeting We sat in the car and cried. My first thoughts were, how could this happen, how could they do this? Then I had to ring my daughter, Jess. That was the worst. She said she couldn't believe it. She sounded so upset. It was just a complete fog. I remember being in a complete daze when I rang my kids to tell them. It was like I was on autopilot – I couldn't think too much about it or I would have broken down. GRO-C GRO-C GRO-C I couldn't deal with it if I thought I had done something to them.

9. At the time of the diagnosis, I recall it being explained to me that "We are going to get rid of this." In terms of management, I don't think they informed me of any precautions needed for sex. I don't think there was a great deal of information about how to manage the condition or what it may mean for us, as a couple and a family, going forward They just said that they were going to get rid of this.

Section 3. Other Infections

10. To the best of my knowledge I do not believe that I have received any infections other than Hepatitis C as a result of being given infected blood. I was tested for HIV and thankfully, this came back negative. However, the period between being tested and getting the result was one of the more anxious in my life just because of the sheer worry, not only for my own health but for that of my family in case I was positive and had somehow passed it on. It really was too horrible to adequately describe in words.

11. In relation to many of the medical complaints that I now suffer from and have suffered from in the past, I do believe that many of these, if not caused by the infection have been exacerbated by it. Similarly, treatments prescribed for these problems may have been rendered less effective due to the presence of the infection within my system.

12. I initially went for test due to suspected liver problems. I do not know if there has been any lasting damage to my liver caused by the HCV. I have not been made aware of any plans for a liver scan.

Section 4. Consent

13. I do not feel I was subjected to any experimental treatment and I am happy with the care and treatment I received once diagnosed. I would not have let anyone do anything to me that I wasn't happy with.

14. Although I consented to the initial blood test in relation to my suspected liver problems, I was never aware that I was being tested specifically for HCV. As I mentioned nothing was explained about risk in my earlier operation and I certainly did not sign any type of consent that I recall. However, I do believe that I would have died if I was not given blood at the time of that surgery.

Section 5. Impact

15. Three months elapsed between being told I had Hepatitis C and before receiving treatment for it. Those months were awful. I became very depressed, but at the same time I didn't want to take anti-depressants. I have found that my personality has changed, I've been very snappy and short tempered, not like me at all. I knew something wasn't right with me but I had put it down to menopause. It's been really hard on my husband. I snap at him constantly. He never knows the mood I am going to be in and this is difficult for him. He's a protector, and doesn't have any control over this.

16. The way he deals with it is by renovating the house, making it nice for me. Occupying himself to take his mind away from it all. This whole episode, the diagnosis, the treatment and the aftermath could have cost me my marriage – I'm sure it would have destroyed a lesser relationship but fortunately we are very strong.

17. In terms of the physical effects, I had put it down to going through menopause. But in hindsight, I think it was the Hepatitis. My sleeping has always been the same, horrendous. I go to sleep at half-past nine and wake up at two in the morning. I stay awake and watch the telly, then fall back asleep on the sofa. I always suffered from fatigue, sometimes to the point of exhaustion and I simply put all that down to having kids and being a mum, but this all started to happen after I contracted Hepatitis C and thinking back I had some of these problems before the kids came along.

18. I have suffered from joint pain. Again, with age you expect these things but I have had it to some extent for many years. It is particularly noticeable in my wrist and finger joints.

19. Other complications on a personal level are the terrible headaches. I also suffer from sinus problems and these may be partly related. "Brain fog" is also an issue. It is like you can be talking to me and I am completely elsewhere mentally. I have been told that it looks like I am looking straight through someone as they speak to me. I general, I have had ongoing problems with memory recall. I should say that none of these were issues that I experienced in my earlier life prior to my operation.

20. Similarly, about 6/7 years ago I started having problems with my teeth. Not just one or two, all of them. They started to become loose. I saw my dentist but she couldn't provide an explanation despite a number of visits and tests. I lived and ate very healthily and had a good oral care regime. I had no obvious gum disease but yet many of my teeth eventually had to be removed including all of my top set.

21. Another issue relates to my fingernails. They were fine and healthy in my younger years but after the time of the ectopic pregnancy, they became brittle and stopped growing. However, since receiving the treatment for the HCV and clearing the virus the growth has resumed and they are healthy and normal once again.

22. One medical complication which I am currently suffering with is lichen planus, which is an itchy rash on my private parts. When researching it recently, I read that it was connected to Hepatitis C. I have been trying to get HRT treatment to combat this, not realising that the Hepatitis C has most likely caused it. GRO-C GRO-C As I've already said, if it wasn't for the strength of our relationship these complications – all caused by this infection that I had no control over getting - could easily have cost me my marriage. That's been the worst part, the hurt and pain it has caused to such a wonderful man.

23. I told my sister about my infection only after I was cured of Hepatitis. I felt dirty, I didn't want anyone to know. But was much harder to tell my kids. I felt devastated and ashamed. My daughter is a sister in A&E and she sees a lot of bad people, people who inject. For me to tell them that I had Hepatitis C was hard. To see their faces – I'll never forget the look on their faces.

24. When I first found out I was infected, I didn't want to touch anyone or for anyone to come near me. I didn't want my husband near me because I felt dirty and unclean. I pushed him away causing more anguish for him. I was particularly worried about my grandkids. What if I wanted to kiss my grandchildren or they I? Or they wanted to wear nanny's clothes or nanny's lipstick? It interfered to such a degree in my relationship with them. If my grandsons play rough and there's blood, I really worry - recently one of them cut their knee and I was filled with dread at what

the possibilities may be – even though I now know the chances of passing anything on are extremely remote.

25. I would never tell my friends, I'm too ashamed, only my family know. When I told my sister and niece a few months ago, they were devastated. My sister became a nan herself for the first time very recently, I was frightened to hold her grandchild. I still haven't held him, I don't feel I can hold him and kiss him even though I'm all clear. I know that's crazy. But I don't know what they would think, and I don't want to put them in the position of being worried about it themselves. My sister tells me it's ridiculous, but it's in my head. I can only hope that time will lessen these fears that I have.

26. I never really drank alcohol but now I don't drink it at all. When you have eight grandkids you can't really be hungover. It hasn't really impacted our social life too much although early on I did not want to see anyone or go anywhere.

27. I have a good job in the village, I only do 12 hours but I have a lovely life here where I live. But when I found out about my infection I was really conscious of touching anyone, I just felt dirty and ashamed. Nobody knows about my circumstances as it is a private family matter. I live in a tight-knit community and I am not sure how it would be received if they did find out.

Section 6. Treatment/Care/Support

28. When I went to my GP a couple of months ago about my depression it all came to a head and I ended up breaking down. It was just everything became too much and it got on top of me. They prescribed me anti-depressants. I didn't want anti-depressants, I didn't want anything in my body. Using this type of pill is not my way. I feel fine now so I have stopped taking them.

29. The treatment I received for the HCV included taking Mavriet, and a combination drug of Glecaprevir and Pibrentasvir. The dosage was three tablets once a day for eight weeks. I experienced some headaches whilst taking the treatment and finished it on 09 July 2018. **(See Exhibit WITN0948003)**

30. At no stage during the diagnosis or subsequent visits or during treatment was I offered any psychological support or assistance. Nor was any offered to my husband or other family members to help them cope with their personal traumas brought about by the infection.

Section 7. Financial Assistance

31. The specialist I saw at Wrexham Maelor Hospital mentioned to me that I could make a claim. My children also believe that 'they should pay for this'. I am in the initial stages of making a claim with the NHS Business Services Authority.

32. There were expenses associated with travel to and from hospital and appointments as well as losses incurred by my husband when he accompanied me but these were insignificant when set alongside the magnitude of the diagnosis itself. It did not affect my work regime as I am part time.

33. I have written to Basildon Hospital in an attempt to retrieve proof of my transfusion. They wrote back stating that "We have checked all the patient health records information systems and can confirm in line with Records Management Code of Practice, we no longer hold records for your blood transfusion." **(See Exhibit WITN0948004)**

34. In absence of evidence of my blood transfusion, I requested verification from Wrexham Maelor Hospital to support my claim to England Infected Blood Support Scheme. In a letter from a Hepatology Nurse, sent on 24 October 2019, the nurse was unable to verify whether I

would have had a blood transfusion and recommended that this would need to be obtained by an obstetrician. **(See Exhibit WITN0948004)**

Section 8. Other Issues

35. I do think that there should be more help available to those who have been infected through no fault of their own. Where are the counselling services? Why is it so difficult to make a claim? All the onus is on the person infected. I can understand it to a point but having to prove you had a blood transfusion so long ago with records destroyed and the changes in the interim within the health service, is such a difficult and frustrating process.

36. No one has accepted responsibility for the whole affair and it could undermine your confidence in the NHS, in the whole system. I for one will ask more questions in the future My doctors, on supplying their diagnosis were quite happy to assume that my infection was via the blood transfusion – where else could I have contracted the virus? - yet it seems that EIBSS will be unwilling to accept that. Why is that the case?.

Statement of Truth

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

Signed GRO-C

Dated 13th January 2020