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Witness Name: Jacqueline Anne Raynel
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INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JACQUELINE ANNE RAYNEL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6 November 2018. For ease of reference, I have followed the formatting of the Rule 9.

I, Jacqueline Anne Raynel, will say as follows: -

Section 1. Introduction

1. My name is name is Jacqueline Anne Raynel. My date of birth is **GRO-C** **GRO-C** 1967. My address is known to the Inquiry. I currently work as a coach for WW (Weight Watchers) Formerly, I was the director of Lylac Ridge, a third sector organisation aimed at providing opportunities for disadvantaged children and young people using Animal Assisted Therapy. I am married with two children, a son aged 32 and a daughter aged 26. I live in Wales.

2. I intend to speak about my Hepatitis C virus ("HCV") infection that I contracted as a result of being given transfusions of contaminated blood. In particular, I intend to talk about 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.

Section 2. How Infected

3. In 1990 I fell pregnant for a second time. At the time, my son was about four years old. One day, I was at home with my son when I started haemorrhaging. At first, I didn't make a fuss but the bleeding became so heavy that I ended up going to The Royal Gwent Hospital in Newport, Wales.

4. When I arrived at the hospital I realised the situation was much worse than I had thought, I had lost so much blood. I don't know how much blood I lost, the details didn't seep into my brain at the time, but it was a lot. The hospital had to give me a blood transfusion. I had already lost my child as a result of complications.

5. I had an immediate allergic reaction to the blood transfusion and fell in and out of consciousness. The allergic reaction prevented my body from regulating its temperature. One minute I was boiling hot and there would be fans and ice on me, the next minute I would be freezing and the hospital staff would strip the ice from me and put blankets on me. Although I was aware what was happening, I had no control over my body. I was shaking and couldn't stop it. I think the allergic reaction went on for 12 hours or so but the details are quite sketchy.

6. As far as I can recall, I was given blood and not blood products. I think my blood type is rhesus AB negative, which is rare. I don't think the Hospital should have given me blood, as I have been told that people with rhesus AB negative blood can't receive blood transfusions. My mother and sister have the same blood type and have been told they cannot receive blood transfusions. The Hospital should have known my blood type as I had given birth to my son there.

7. While I was in hospital, no information was given to me about the blood transfusion or the associated risks. The staff treated me, told me I was better

and released me into the care of my GP who I saw regularly for check-ups. My GP was happy with my progress.

8. Immediately after my hospital admission there were no noticeable ill effects. I was often tired and exhausted but I put this down to having a young son. I then had a second child, which added to my tiredness.

9. In 2005 I started to develop acid reflux for which I was prescribed Omeprazole and Ibuprofen and later Rofecoxib in Ibuprofen's place. The drugs made me absolutely exhausted. Where I used to sleep six hours a night I was now sleeping twelve. In the space of six weeks, I had put on a stone and a half of weight. I could no longer run up stairs and struggled to even walk a flight of stairs.

10. I went to the GP who said there was nothing wrong however I knew that wasn't right. My work sent me to a Harley Street physician who sent me on to the Heath Hospital in Cardiff where I saw a liver specialist. He told me to stop taking the medication immediately as my liver enzymes were something like 141. He told me Rofecoxib was in fact banned as it caused liver damage. He didn't test me for HCV and I wonder now if I became so ill because my liver was already inflamed from the HCV. After I stopped taking the medication, I got better but I didn't go back to 100% fitness.

11. When my children were older, I went back to work. I started off as a high level administrator but moved on to become a national key accounts manager for a large construction firm. In my role, I was responsible for looking after projects valued between £50 million and £100 million pound. My job was demanding, and I often worked 60 to 70 hour week but I loved it.

12. I had always prided myself on my ability to manage both a demanding job as well as take care of my children and husband and keep a tidy home. It started becoming hard to balance both home and work life. I was exhausted

all the time. I couldn't lift my head off the pillows and I struggled to get up in the morning. At the time, I put my exhaustion down to stress.

13. I wasn't coping. It was like a complete fog had come over my brain. I wasn't able to keep up at work and I was falling behind in my family duties. I was forgetting to do the shopping, forgetting to pay bills. It all became too much and I came to the decision to ask for a redundancy. I walked away from my job and took a year off to try and recoup.

14. While on my break from work, I began to develop Lylac Ridge, a third sector organisation aimed at engaging disadvantaged children and young persons through animal assisted therapies. I put everything I had into Lylac Ridge and secured a large amount of government funding for our programs. At one stage, we had over a hundred animals on the farm and many clients.

15. The brain fog continued and got worse. It got to a point where one day I couldn't remember what a fork was called. I knew what it did and how to use it but I just couldn't remember the name of it. I felt mentally broken. I had joint pain, bleeding gums, loss of hair, tiredness, really bad stomach pain and nausea. I was at my lowest.

16. By November 2016 I knew my tiredness, nausea and lack of brain function was more than just stress. I felt like I was operating at 30% capacity when I was used to operating at 120% capacity. I went back to my GP who ran some tests. My GP was Mr Finch at the Wellspring Medical Centre, Risca. My doctor discovered my liver was enlarged and I had developed diabetes type 2. The gastroenterologist booked me to have both an endoscopy and sigmoidoscopy which detected issues with my stomach and colon.

17. Over the next few months, I began to change my diet as recommended by my GP but I still felt awful. I thought there was more to it, and I asked the doctor to run more tests. All the test results came back clear except the HCV results, which hadn't come back. My doctor told me not to worry about HCV, as I didn't fit the demographics.

18. In February 2017 my doctor called me and asked me to urgently come to the clinic. I remember thinking I must have cancer. I attended the Clinic and my doctor told me I had HCV. The initial shock blew me away. I didn't really understand what HCV was, but my doctor gave me leaflets and brochures to read. At the time, I didn't really take it in. I just remember being happy I didn't have cancer. That was the only thing in my head. But then I realised that HCV was quite serious.

19. After learning I was infected, my first question was how was I infected? My doctor told me she didn't know and it wasn't something that should take up my time and that the thing to focus on was getting healthy.

20. My doctor was fantastic. She gave me information brochures about HCV and gave me advice on precautionary measures to take. She also directed me to the Hepatitis C Trust's website and asked me not to get information on the Internet from sources other than the Trust.

21. I found the sources provided to me helpful. Prior to my diagnosis, I didn't know a lot about HCV or how you got it. I had always associated it with drug users. While waiting for my treatment I watched the panorama programme around infected blood and the effects this had had and why? This programme made me feel more informed as to how I may have contracted the disease and put me at ease for that, but seeing the long term of effects prior treatments had had on people and their life style now made me very scared and anxious about my future.

22. My GP referred me to Mr Gavin Hayes, an hepatologist nursing practitioner at The Royal Gwent Hospital for treatment. It was Mr Hayes who told me that I was most likely infected when I received the blood transfusion. I was shocked, as this hadn't been mentioned to me previously.

23. Mr Hayes provided me with booklets outlining available treatment options. I looked into the drugs and made the decision not to go ahead with treatment

after reading that interferon was similar to chemotherapy and left patients bed bound for days at time. When I told Mr Hayes my decision, he reassured me that interferon was no longer used and I could be treated with less harsh medicines.

24. All the medical professionals I dealt with were fantastic. I have seen more doctors in the past 18 months than the preceding 18 years and I really feel like the NHS has treated me like royalty. Despite my infection, I still have faith in our NHS system.

Section 3. Other Infections

25. I was told when I went to donate blood that there is a possibility that I may have been given blood infected with variant Creutzfeld Jacobs Disease (vCJD) but that there is no way of knowing and for this reason, I will never be able to donate blood.

Section 4. Consent

26. I believe I have always been treated and tested by medical professionals with my consent and knowledge. I don't really remember but the doctors probably told me that I needed a blood transfusion and I would have told them to do what's necessary. My memories from the time are shrouded by the sense of fear and worry for my son that I felt then.

Section 5. Impact

27. The HCV diagnosis broke me. I don't think I have ever felt so scared. It was traumatic. In many ways, the diagnosis became my life; it was all I could focus on. I withdrew socially and entered a massive depression. I had previously been an open, social person but after my diagnosis I stopped going out and avoided people as much as I could. I had always welcomed people in my home and loved spending time at the Lylac Ridge farm but

after my diagnosis I couldn't spend more than two hours with people before needing to walk away.

28. I began to develop panic attacks, which I feel silly saying because I didn't even know what I was panicking about. My heart would race and it felt like I couldn't breathe. I didn't feel like I could talk to my family about it because I felt silly and weak.

29. The hardest thing for me was not knowing whether I was going to live or die. I really thought I was going to die. It upset my family because I started putting things in place in the event I died. My daughter is GRO-C GRO-C and my main concern was who would take care of her after I was gone. I would argue with my husband and family, they would tell me to stop being silly, stop having silly thoughts. It was like I had lost my confidence to live.

30. I became angry. Angry with anyone and everyone. Anger was never something I had adopted but after my diagnosis my tolerance levels were completely diminished and I had no patience for anything. I became intolerant of people having normal conversations about trivial things. I didn't want to talk about everyday life; it didn't seem relevant to me.

31. My diagnosis and illnesses had a large impact on my family. Financially, it was very difficult and I felt my husband hid away in his work. Because he was busy supporting the family financially, I felt he wasn't around to support me, which caused conflict between us.

32. It hit my daughter very, very hard. Her GRO-C and she started GRO-C. Because I had stopped socialising my daughter felt that she could stop as well. I had to physically push her out the door sometimes.

33. My son became fixated on my diagnosis. He compiled folders full of information about HCV, researching the different genotypes and possible

causes of infection. His behaviour became obsessive to the point where I had to ask him to stop and focus on other things.

34. My mum and dad are both quite elderly and worried a great deal when I told them. GRO-C GRO-C. My own diagnosis a few months later became a point of worry for him and in turn a further cause of stress for me, as I worried about my parent's health.

35. I had to walk away from Lylac Ridge as I could no longer manage the operations. It was absolutely heart breaking. So much blood, sweat and tears had gone into establishing it. There were so many people depending on us and in the blink of an eye, everything we had built just seemed to go. HCV destroyed my career.

36. The diagnosis caused a lot of financial stress for my family. I went from having a £500 a week job to receiving a £70 weekly government benefit. I had always supported my family and I could no longer do that. My husband and I used all our savings on living expenses.

37. In May 2017 I started my HCV treatment. I was prescribed ribavirin and two other drugs, the names of which I forget. The side effects of the drugs were minimal however my whole life changed in the following months. I couldn't drive myself anywhere during the first weeks of receiving the treatment due to the effects it may have on me putting more strain on my family and friends to get me to treatments help with basic shopping etc. I had to change my diet and completely cut out alcohol, which was difficult as we were always social people. I felt I had to turn down invitations to parties and functions as I felt I made people uncomfortable.

38. I became quite paranoid about my HCV and the associated stigma. I constantly carried a first aid kid so I was able to decontaminate areas in case I cut myself. If I were to cut myself in the kitchen, I would yell at my family members to stay away.

39. For the same reason, I stopped going to the dentist or to hairdressers. I felt that some of the dental clinics I attended treated me differently when I told them I had HCV. The staff would make a big deal about putting on gloves and protective clothing. I know they were just taking precautions but it felt over the top. I have since found a great dental clinic where I feel comfortable.

40. The treatment ended in middle to late August. During treatment I saw Mr Hayes every week, or at least it felt like I did. Mr Hayes would regularly check my bloods and run liver scans. When my liver was first scanned, my Fibroscan levels were sitting at around 17.8 where the maximum is 9.5. A year after treatment, my liver levels are down to 6.6. Mr Hayes has told me the HCV is no longer detectable and I now only need to see him every four years.

41. After I was told my HCV was no longer detectable I went to donate blood but my donation was refused and I was told there was a risk I could be infected with vCJD. This was the first I had heard of vCJD and it distressed me to learn I could be infected with it.

42. After that experience, I recalled receiving a letter back in the 1990s after my blood transfusion telling me I could no longer donate blood. I don't remember who sent me the letter or if it explained why I could no longer donate blood. Thankfully, I didn't donate blood between the time I received my blood transfusion and my diagnosis. I would be absolutely devastated if I had infected someone with HCV.

Section 6. Treatment/Care/Support

43. I didn't encounter any difficulties receiving treatment. My medical professionals did tell me "whatever you do, don't move out of Wales" because I would not be able to access the same treatment or support. This I found quite distressing. To me, it shouldn't matter where you live in the country, you should get exactly the same treatment from the NHS.

44. I haven't accessed any social or support groups because there don't seem to be any in my area. There are many online support groups but I think I would prefer the face-to-face support. I have thought about establishing a support group.

Section 7. Financial Assistance

45. I found it very difficult to get financial help. When I was first diagnosed, my work paid me statutory sick pay for 26 weeks. After that 26 weeks, I had to go on ESA, which lasted the duration of my HCV treatment.

46. When my HCV was no longer detectable, the government said I was no longer eligible for ESA payments as I was no longer sick. This was despite my hepatologist providing a letter confirming that while my HCV was no longer detectable I was still not well enough to go back to my former job. The Welsh Infected Blood Service also wrote me a letter of support. The government still declined the payments because an occupational therapist (OT) had said I could pick up a phone, walk to a bus and therefore work. The OT's assessment overruled my doctors.

47. When my ESA payments ran out, I was told by the government to go on unemployment benefits.

48. Then at the end of September 2017 I received a £20,000 payment from the Skipton Fund. The application process was difficult, and it took months to get all the various documents signed by the relevant medical professionals. However, once the application was approved I wasn't challenged on any aspect of it. I think this was because all my medical records were available.

49. In November 2017 The Welsh Infected Blood Service (WIBS) told me that I qualified for a monthly payment of £345. I was told this payment will carry on until either I was dead or the money runs out, whichever occurs first.

50. When I left my job, I lost access to my company car so I used the compensation money to buy myself a new car. When WIBS discovered this, they took the receipt and refunded the value of the car. They also funded a respite holiday. In total, I think WIBS paid me around £5,000.

Section 8. Other Issues

51. The main thing I want to come from this Inquiry is for there to be some accountability for what happened. Someone needs to take responsibility for allowing this to happen to myself and countless other. Someone knew about the infected blood but still allowed it to be used. In all my jobs, if something went wrong or if someone died then I was accountable. It was part of my job. It should be the same for others. I think the lack of accountability is absolutely disgraceful.

52. To me, the financial side doesn't matter so much. I worry that any compensation will come out of the NHS meaning other people won't have access to treatment.

Statement of Truth

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

Signed GRO-C

Dated 9/3/19