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Witness Name: ELAINE PARKER

Statement No.: WITN0737

Exhibits: Nil

Dated: 11 February 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ELAINE PARKER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 January 2018.

I, ELAINE PARKER, will say as follows: -

Section 1. Introduction

1. My name is Elaine Parker. My date of birth and address are known to the Inquiry. I am a wife, mother and grandmother. I intend to speak about my Hepatitis C (HCV) infection, of which I am now thankfully cleared. In particular, the nature of my illness, how the illness affected me, the treatment that I received and the impact it had on me, my family and our lives together.

Section 2. How Infected

2. I was infected with HCV in August 1985 through a blood transfusion at Dunedin Hospital in Reading, Berkshire. I went into hospital for a hysterectomy, but the procedure went wrong, and I ended up having three operations in three days. During the third operation, I lost seven pints of blood. As a result, I had a blood transfusion. I was told that the hospital had to call out for blood specifically for me as my blood type is O-Negative.
3. I was not consulted about having a blood transfusion and therefore was not made aware of the risk of being exposed to infection. In fact, I only found out that I had had the transfusion a week afterwards. At that point, I had not left the hospital since the operations.
4. The doctor, whose nickname was "The Butcher", told me that the blood transfusion was my fault. I had coughed which caused a stitch to split. This led to haemorrhaging which the hospital staff tried to stop by packing and suctioning. When these methods failed to stop the bleeding, they resorted to another operation and a blood transfusion because of the extent of the blood loss.
5. I was very ill in the two weeks after the transfusion, and I lost two stone in two weeks.
6. I only found out that I had been infected with HCV in 1995. After I had donated blood, I received a letter from the National Blood Service notifying me that I had HCV. Historically, I have been a regular blood donor but had not donated for a number of years prior to this donation as I was taking statins. Before this donation, statins prohibited one from donating blood. These rules changed which is why I then donated blood.
7. One of the side effects of statins is that they cause abnormalities in liver enzyme tests. When I had blood tests prior to 1995, they always reflected

irregular liver function, but I was advised that there was nothing to worry about and that the statins were the cause of these results.

8. The letter that I received from the National Blood Service stated their routine tests showed that I had HCV, which they described as similar to HIV but not as bad. I received no further information or advice about managing or understanding the infection. I felt that the letter was cold and uncompassionate.
9. Immediately after I read the letter, I called my GP. I was hysterical. He said that I should come to his rooms immediately, which I did. I met with him for an hour and a half. He did not know very much about HCV but he suggested that I go to Southend hospital for further tests. He also asked whether I had used drugs and whether I had piercings. When I said that I did not, he told me that it was very likely that I was infected when I had the blood transfusion.

Section 3. Other Infections

10. I have not received any infection or infections other than HCV as a result of being given infected blood or blood products.

Section 4. Consent

11. I do not believe that I have been treated or tested without my knowledge for the purposes of research.

Section 5. Impact

12. As my GP recommended, I went to Southend Hospital for further blood tests. They decided that I should have a biopsy in order to assess the damage to my liver. The doctor who saw me was an Iranian woman who

was wonderful. My experience of the biopsy, however, was not. There was no bed for me so I was put into the geriatric ward. When it was time for the operation, the nurses could not find me. I had to make my own way down to the operating floor. I found the experience distressing.

13. After the liver biopsy, I was told that the type of HCV that I had was the hardest to cure but that my liver damage, on a scale of one to four, four being the lowest, was only a four. I began my Interferon treatment and had injections three times a week. The treatment made me feel horrible. After each injection, it felt like I had been given a dose of the worst case of flu. My hair thinned and I had a constant dry mouth. I also started smoking – a habit I haven't manage to kick.
14. The injections were very inconvenient and I had to plan my life around them all while continuing my work as a bookkeeper at a cleaning contractor where I worked at the time. At first, I could not inject myself so I used to go to the doctor for the injections. After a while, my husband learned to inject me. Shortly after that, I learned to inject myself – mostly in my stomach and legs. Though this was more convenient, I was still exhausted and fluey all the time. I was lucky that the firm for which I worked was very understanding. I did not go in to work when I felt too ill to do so.
15. During the year of my Interferon treatment, my HCV tests came back negative. I went off the treatment and hoped that I was cleared.
16. I subsequently went for a blood test and was told that my HCV result was positive. I was absolutely devastated. As I walked out, I was sobbing. It felt so unfair. I was so angry, I kicked a car in the parking lot, an action that is completely out of character.
17. After that, I was referred to the Royal Free Hospital for a second attempt at treatment. I was put onto Interferon again. This time, it was combined with

Ribavirin, which I understand was a clinical trial at the time of my treatment. Come to think of it, I cannot be certain about whether I was receiving the drug or a placebo. I had all the side effects of Interferon as well as developing eczema. I used to fall asleep all the time – at the dinner table and in similar situations. Sometimes I think that I'm lucky that I didn't kill myself while I was driving.

18. After eleven months of treatment, I tested positive again for HCV. I was told that there was no more that the doctors could do. I was told that if my liver deteriorated further, I may need to have a liver transplant. In that case, I would be added to the list of recipients.

19. At that point, my son went off the rails. He overheard me telling a friend that no more treatment was available to me. GRO-C
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GRO-C Thankfully, he calmed down after my husband and I spoke to him about my infection.

20. Those three years of my life are years that I do not remember well. I am lucky to have been supported by my husband throughout those years. My children and my friends were also very supportive. They knew that the infection was not my fault.

21. I would say that any stigma that I experienced was self-imposed. I felt contaminated and dirty. Even though being an organ donor was important to me, I ripped up my organ donor card. I felt that nobody would want my dirty organs.

22. I was always very aware of protecting people from my infection. I did not ever want to contaminate anyone. I would burn all the plasters and bandages that I used – something I do to this day. Once, I fell off a ladder at work and cut my toe badly. I started vomiting when I saw all of the blood.

Still, I was adamant that nobody should help me with the clean-up. I was so scared of contaminating others.

23. Things were also difficult with my baby grandson. My son-in-law, his father, was not happy with my touching the baby. After a lot of explaining, he came around. But I was still worried and very cautious. Once, I was changing my grandson's nappy when I pricked myself with the safety pin. I was so nervous about it. I burned the pin and burned the nappy even though I knew that none of my blood had spilt. These small events were my reality. Perhaps part of the reason for my paranoia was that I was not given much advice about how to handle my infection at home.

24. Perhaps my husband had some experience of the stigma associated with my infection. He was told by the Blood Donation Service that if he wanted to donate blood, he should stop living with an HCV-infected person.

25. Thankfully, things took a turn for the better after the second round of treatment failed. I was in a Holland & Barratt store exploring alternative medicines to treat my liver. The assistant enquired about my condition and I told her that I was infected with HCV. She recommended that I try taking milk thistle. Shortly after I started taking it, my HCV tests came back negative and have been negative ever since. I am so grateful.

Section 6. Treatment/Care/Support

26. My GP offered me counselling but I rather deal with my diagnosis on my own. I dealt with it by telling the people around me about my infection. I had no problem being open because I knew that it was not my fault. My GP also suggested that I take life easy, but I didn't really take this advice. He was incredibly kind and supportive. I was lucky.

27. In fact, I feel very lucky in general. When I was first diagnosed with HCV, I was frightened that I would not live long enough to see my children grow

up and have families of their own. Thankfully, this has not materialised. I have four wonderful grandchildren. Life is very good at the moment. I am now clear of all infection and I have a wonderful life. I go away every weekend with my husband. When I was ill, he began fixing up boats. I think that was how he dealt with my infection. Since then, we have had a boat and we love going on boating holidays.

28. I feel guilty about how lucky I am. At the time of the preliminary hearings held by the Inquiry, I felt that I could not face being in the presence of so many people who are not as lucky as I am – people who are still suffering or whose loved ones have died. For this reason, I am not sure whether or not I want to come to any of the Inquiry's hearings. Perhaps I will change my mind closer to the time.

Section 7. Financial Assistance

29. During the 1990s, I contacted some solicitors about the possibility of compensation. I was advised that there were no claims that I could make.

30. I was lucky to find out about the Skipton Fund when I was waiting for treatment at the Royal Free Hospital. I was chatting to a man in the waiting room who told me about the Fund. I then asked the doctor who confirmed that I was eligible for financial assistance. I then applied for compensation. The process took some time and I had to figure it out myself. I had to go back to Dunedin Hospital to get copies of my medical records and the notes made during my blood transfusion.

31. I received £20 000 from the Fund, and I still receive monthly payments – one of £333, and one of £144. I also get £500 annually to put towards heating.

Section 8. Other Issues

32. I did not feel angry about my infection with HCV until a few years ago when I heard that the medical community had known about and covered up the fact that the blood was contaminated. Prior to that, I had seen myself as lucky to have had the blood transfusion – if I had not had it, I would have died. For that reason, I saw all of my life after 1985 as a bonus. Now, I want people to be held accountable for what they have done. If people have caused death and suffering, they should not get away with it. I want them to be named and shamed.

33. Since the Inquiry was announced, I have thought a lot more about that period of my life. It's always there now, whereas before, it had gone away. It has become raw again. When it hit the headlines, I demanded another blood test, which I had. It came back negative. People have been phoning me to speak about what they have seen on the news. It's made me angrier than I ever was.

Statement of Truth

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

Signed

GRO-C

Dated

12 February 2019.