

Witness Name: Elaine Iljon Foreman

Statement No.: WITNW0227001

Dated: 24/5/19

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ELAINE ILJON FOREMAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 January 2019.

I, Elaine Iljon Foreman, will say as follows: -

Section 1. Introduction

1. My name is Elaine Iljon Foreman. My date of birth is GRO-C 1955 and my address is known to the Inquiry. I am a clinical psychologist in private practice. I intend to speak about my infection with Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.
2. I confirm that I do not have legal representation and that I am not seeking anonymity.

Section 2. How Infected

3. I was diagnosed with Von Willebrand Disease aged about 18. My family had a history of this coagulation deficiency.
4. In approximately 1973-1976 (I cannot remember the exact date, but it was during my psychology honours degree), I had to have a cyst removed. In anticipation of the bleeding that could occur during the surgery, my doctors at Durham Hospital administered what was probably some Factor VIII product to prevent bleeding. I presume this is when I was given infected blood product.
5. I have never had tattoos or used drugs, especially considering I was afraid of needles before I underwent treatment for my Hepatitis C infection.
6. In 1990, I found a breast lump. I was referred to the Royal Free Hospital for tests. The lump was found to be benign and I was relieved. I initially feared I might have breast cancer. However, the investigation of the cause of the lump revealed abnormality in the blood tests.
7. I did not know my doctors were testing for Hepatitis C, but I was aware they were concerned about my liver and taking further blood to test. I was then told I had asymptomatic Hepatitis C infection. This was my first awareness of the infection. The blood tests had revealed extremely active Hepatitis C, but I was asymptomatic. I was told the virus would quietly continue to destroy my liver, until one day I just would not wake up.
8. I was under the care of Professor Dusheiko and he and his team were excellent. I was well informed about the illness and how to care for myself.

Section 3. Other Infections

9. As far as I am aware, I was only infected with Hepatitis C. I presume I was tested for HIV but I can't be sure.

Section 4. Consent

10. I was unaware I was being tested for Hepatitis C when that test was carried out and the diagnosis made. A stated, I presume I was tested for HIV, but again if so, I was unaware of the specific nature of the test. However, my overall care was excellent and I was kept well informed and consented to all subsequent treatment.
11. I also agreed to be tested for the purposes of research. I was in Oxford for a job interview. I did not feel well. I believe this was after my diagnosis in 1990. I left the interview and went straight to casualty at the John Radcliffe Hospital. I was diagnosed with meningitis. I required blood products because of the procedures that were necessary as part of my treatment, such as a spinal tap. I was asked to take part in a study to see if heat-treated blood products were safe. I agreed and they gave me the heat-treated product. As far as I am aware, the products were safe. However, I do remember seeing my file and it had a red sticker on it saying "Danger: HIV risk". Whilst I understood the purpose, it was still horrifying to see that I was considered a HIV risk.

Section 5. Impact

12. I understand there was, and may still be, physical damage to my liver from the Hepatitis C. I understand this from what was said to me at the time by the team at the Royal Free. I had to undergo regular follow-ups and blood tests. I have not had any tests or follow

up in about fifteen years now, which I am glad about, most of all for my recovery, but also as I've never liked hospitals and particularly detest their parking processes and cost. Fortunately, my Von Willebrand Disease has changed over time and now I am in the lower levels of normal clotting so I no longer require blood products.

13. Mentally, I have always managed. However, the knowledge of the infection was hard and there was an ever-present fear of passing the infection to someone else. The uncertainty of whether the still largely experimental treatment would cure this potentially terminal illness was a constant threat I had to live with and it certainly was not a pleasant time to say the least.
14. Each time there was a planned stoppage of treatment, the wait for the blood tests and the results to establish whether the Hepatitis had returned was an extremely frightening time for both me and my family.
15. When my infection was diagnosed, I was told I could no longer drink wine and this was a bit sad. I lost much of my hair which I think was due to the effects of the Interferon chemotherapy, though I cannot be sure if this was Hepatitis C related too.
16. I am not sure that I would have noticed many of the physical symptoms of the disease as I was very fit at the time and I could until then normally push my body to extreme limits without ill effect. I have never been as fit as I was at the time of diagnosis and the start of the treatment. I am still saddened by this. Losing that level of fitness has impacted on my self-image, which has meant that I have never regained that level of self-assurance and self-confidence.
17. Even though I am now clear of Hepatitis C, when I plucked up the courage up to donate blood I was told I could not do so.

18. The treatment and the knowledge I had Hepatitis C did not make me feel good about myself and it was not a pleasant time, but I am thankful I was asymptomatic for so long and that I was very physically fit, as I believe this helped in my recovery.
19. Socially, I have only ever mentioned it in passing and people have been reasonably sympathetic. If anyone no longer wanted to be my friend because of my infection, I didn't notice them leaving my life.
20. I have not experienced any stigma because of my infection.
21. The infection did not impact my education, to the best of my knowledge.
22. The infection may have impacted my career. During treatment, I was certainly not performing at my best, but I do not know where my career would be had I not been infected.
23. Financially, I have not noticed any adverse impact. I do declare the infection for insurance and such, but have not noticed any particular cost increase.
24. The infection did impact my family. Overall, they were very supportive. However, they were worried as the treatment was only experimental at the time and had no guarantee that it would cure me or that the Hepatitis C would not come back. I feel this was very distressing for both them and for me knowing that I was the cause of their worry.

Section 6. Treatment/Care/Support

25. I was treated with Interferon injections. The treatment itself was very unpleasant and distressing. I was mildly needle phobic and so injecting myself 3 times a week with a total of 18 million units a week of Interferon injected into the stomach was awful. My hair fell out and has never been the same since. This definitely impacted on my self-image and still does to this day. The treatment interfered with travel as I had to carry syringes with me and store the treatment properly and this would lead to uncomfortable questions.
26. When I began treatment, I was participating in the rock and roll championships and represented Britain for 3 years from 1987-1989. However, once I started treatment I could no longer compete, as I was not well enough. The treatment affected my energy levels, my focus and concentration.
27. I had to stop gym workouts, and functioned with difficulty at work. Chairing a meeting was daunting, as it was difficult at times to concentrate sufficiently to follow the agenda. I had to temporarily give up rock and roll. I knew I had beaten Hepatitis C when I was able to participate in a 12 hour-long event once again!
28. The first round of treatment lasted for 18 months, but the Hepatitis C was still detectable so I needed another course of treatment. In total, I was on Interferon for about three years.
29. I have never been refused other treatment because of my Hepatitis C infection. I do make medical professionals aware and they have worn gloves to protect themselves but this is to be expected. I have never faced obstacles in obtaining treatment or been refused treatment I feel I should have received.

30. I have never been offered counselling or psychological support, but I do not feel I have needed it and Professor Dusheiko's team were very supportive.

Section 7. Financial Assistance

31. I discovered the financial support available to me many years after my diagnoses. In approximately 2007, I attended a study at the Royal Free Haemophilia Clinic to help them out with a family study. I was asked if I was aware of the Skipton Fund and when I replied no, I was given details.
32. I completed the application and subsequent forms I have been sent by Skipton, which is now EIBSS. I receive quarterly payments and I am very appreciative of the support given.
33. As far as I recall, there were no preconditions to receiving the money.

Section 8. Other Issues

34. In the same way as finding out by chance that I was eligible to apply for the Skipton Fund, I have now as a result of offering to assist with the Inquiry by providing a statement, made another very important discovery. I happened to see a reference to the criteria for Special Category Membership (SCM) criteria which stated the applicant needed to have had autoimmune disease which was due to, or worsened by, interferon treatment, and that this included rheumatoid arthritis.
35. I did some internet research into the symptoms of rheumatoid arthritis and found that many of these were descriptive of my state post interferon treatment. I am now in the process of having blood

tests for rheumatoid arthritis. The symptoms I have experienced, and their relevance to the research are detailed below:

36. It appears that I should have applied for SMC, given the appearance and subsequent exacerbation of rheumatoid arthritis symptoms following interferon treatment. I was unaware of the direct link between the treatment and this condition. As a successful stage 1 applicant, with progressively worsening arthritis, I now realise that the Hepatitis infection and subsequent treatment is likely to have led to this associated condition. I did not mention it before believing it was simply age related and possibly accelerated by my dancing activity.
37. The arthritis is undoubtedly having a long-term negative impact on my ability to carry out daily activities as it affects mobility, flexibility, and gives rise to very distressing levels of pain and at times debilitating stiffness. This has meant that I have been and still am affected in performing my daily duties due to the infection and the treatment.
38. The areas affected by rheumatoid arthritis include both knees, and both wrists, consistent with the finding that rheumatoid arthritis typically affects the joints symmetrically. In addition, I have atrial fibrillation and foot distortion.
39. The onset was initially sudden – in the mid to late 1990s I experienced increasing hip and lower back pain which affected my mobility and was very painful to move and even to drive my car. I understand these too are symptoms of rheumatoid arthritis I also had weight gain, and felt low and depressed, as well as having low energy, considerable tiredness and feeling ill much of the time. I went to the osteopath who was also a friend, as my GP and physio couldn't help. The osteopath commented on my weight gain and mood state, and said I appeared to be locked in a straight-jacket.

40. I learned from my research that if rheumatoid arthritis is not identified and treated it can contribute to long term damage of joints, both destruction and deformity. My left foot has developed a bunion, the right has a change of shape, and at times I experience foot pain. All of this is concerning given the additional exacerbation of the wear and tear of osteoarthritis on my knee joints linked to rock and roll dancing.
41. Over the years post treatment, my arthritis has required 4 arthroscopies, 2 per knee. I am now informed that in the foreseeable future I will also require double knee replacements. (I also have osteoarthritis as well). This is extremely distressing as I understand that replacement of these joints is a major operation that involves several days in hospital followed by months of very painful rehabilitation.
42. What is even more disturbing is that it appears the latest joints have a limited lifespan of 10 to 20 years, are by no means perfect and that some function may not be restored after the damaged joint is replaced by a new one. This is a very depressing and worrying prognosis.
43. In addition, I have required surgery for carpal tunnel syndrome to both wrists. I understand that rheumatoid arthritis is one of the most frequent conditions linked to carpal tunnel surgery.
44. As mentioned, I have also had a diagnosis of Atrial Fibrillation and am on medication for this. It appears that rheumatoid arthritis increases the risk of having atrial fibrillation, and this in turn leads to an increased likelihood of other heart disease including heart attacks and strokes.
45. The main symptoms I have experienced from rheumatoid arthritis are joint pain, marked swelling, stiffness and inflammation. My knees are often inflamed, becoming hot, red, and tender to the touch. The pain is frequently worse in the mornings hampering getting out of

bed. Likewise getting up to go to the toilet during the night can be difficult because of the prior period of inactivity. At times it has even hampered getting up after a meal at a restaurant, or out of a vehicle after a long journey. There is considerable stiffness to the knee joints which makes going up and particularly down stairs very difficult, requiring stepping with 2 feet per step and supporting my weight on the handrail. The stiffness too is more severe in the morning or after a period of inactivity. It usually lasts several hours.

46. Periodically I experience neck, shoulder, spine and hip pain. This too follows an intermittent pattern with periods when it flares.
47. One further symptom which again my research suggests is linked to rheumatoid arthritis is having a dry mouth. I now require a bottle of water by my bed, something that never happened pre-interferon, as I often awake with an extremely dry mouth.
48. Over the years I have sought help many times, through my GP and via private medicine, and been referred to physiotherapy, to the muscular skeletal clinic, and have seen alternative health practitioners including chiropractors, osteopaths, masseurs and a homeopath. There has been occasional improvement, but the nature of the condition is such that further flare ups occur nonetheless on a frequent, though unpredictable, basis.
49. Finally, regarding feelings, it is indeed hard to deal with the unpredictable nature of rheumatoid arthritis. The pain and stiffness at times is much worse than at other times, and there's no way of knowing when a flare-up will occur. I have certainly at times felt very low, and experienced feelings of stress and anxiety. Sometimes these feelings can be related to poorly controlled pain or fatigue. It has meant limiting the amount and skill that I can put into my leisure activity of greatest pleasure – rock and roll dancing. Living with this

long-term condition I believe has contributed to periods of increased emotions of frustration, fear, pain, anger and resentment.

50. I never considered suing because of my infection with Hepatitis C. When I believe I was infected, Hepatitis C had not yet been identified so I do not think there is much that could have been done. I was given blood products to prevent me bleeding and coming to harm, so I do not blame them. I see it as part of my care at the time. I am incredibly grateful for the excellent care I received albeit I believe the virus led directly to the conditions that I now suffer from which I have detailed above.
51. I do not understand what has happened really. If there was a cover up and individuals continued to receive infected products, then that would be awful. However, at the time there was nothing else that could have been done for me so I do not envy the decisions that had to be made by those running the blood service as it must have been difficult.

Statement of Truth

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

Signed GRO-C

Dated 24/5/19