

15 JAN 2019

Witness Name: Derrick Wilks

Statement No.: **WITN0549/001**

Exhibits: **WITN0549/002 - 003**

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DERRICK WILKS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6 December 2018.

I, Derrick Wilks, will say as follows: -

Section 1. Introduction

1. My name is Derrick Wilks. My date of birth and address are known to the Inquiry. I am retired, having last worked for Hewlett Packard. My wife and I have been married for 51 years and we have two daughters together.
2. I intend to speak about my infection with the Hepatitis C virus ("HCV"), which I contracted as a result of being given contaminated infusions to treat my haemoglobinaemia.
3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the devastating impact it has had on my life and the rest of my family.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. I believe I was infected with the HCV in 1994 at the Royal Berkshire Hospital in Reading where I was having fortnightly infusions in the day ward to treat my haemoglobinaemia.
6. As a child and a young man, I suffered with pneumonia three times, at the ages of seven, fourteen and twenty-one. I was also regularly ill with chest infections such as chronic bronchitis and I had to undergo the removal of my tonsils and appendix. I was informed that pneumonia could have a trigger reaction, affecting organs such as the pancreas and the lungs. This affected how I could use the substances I put into my body. If I ate meat and digested it, I would only get 2% of the benefits and the rest would become waste.
7. Due to being ill so often, in 1974, my GP referred me to Northwick Park Hospital where I was introduced to Doctor Webster (now Professor Webster). After conducting several tests on me, including skin and lung tests, Doctor Webster concluded that my blood count was not right. Specifically, he told me that I was not producing enough red blood cells. He identified my condition as hyper haemoglobinaemia, a form of anemia.
8. Doctor Webster told me that the only way to treat my condition was a blood product, specifically gamma globulin injections. He described the product as the "cream of the blood donations", because it was like "full fat milk", taken from the very top of the blood. He put this product into vials and I was required to have two weekly injections of 13.2mls in the backside.
9. I continued with this treatment on every Friday of the week for twenty years, until 1994. I initially received the treatment at my local doctors on Friday mornings and later at home as the nurse administering the

injections lived in close proximity to my house. I also regularly visited Doctor Webster at Northwick Park Hospital for check ups.

10. For the twenty years during which I was using this treatment, it was broadly successful. I felt much better and I would say my health went from 45% to 80%. It enabled me to do a different job full-time and everything was going relatively well at that time. I was still up and down but I would have around one bad week of health to every three good weeks.
11. Towards the end of this period, the procedure was changed and I began receiving my injections in my arms instead of the backside. At the time I was employed as a carpet fitter, doing lots of hours of strenuous work, but doing very well. My quality of life undoubtedly improved overall as a result of this treatment.
12. I would describe these weekly injections as a treatment rather than a trial; as a routine that lasted for a very long time and that was never supposed to come to an end. I have very few records of this period because for the majority of tests and injections, a nurse would simply call me and tell me I needed to visit the GP or the hospital. Unsurprisingly, I did not keep a record of all the calls and letters I received.
13. In 1994, Doctor Webster wrote to me to inform me that he had moved his operation to the Royal Free Hospital in London and that he would be consolidating specialist products there. I went in to visit him, as I was sick of still getting ill frequently and I wanted to know how long I could last on my current treatment.
14. His team's space in the Royal Free Hospital was very bizarre and located underground in the hospital. I used to call it the boiler room. I have never been in another part of a hospital similar to that. Doctor Webster told me that there were no new universally available treatments he could offer me but that he wanted to put me forward to take part in the trial of a new blood product. I soon learnt I had qualified for the trial.

15. Doctor Webster said that the new product was not an injection but an infusion. He said it would be better for me as it would keep me at least as healthy as the injections but I would only need to take it once a fortnight. In reality, I soon found that because of the time it took to carry out the infusion, the fact I had to go to the hospital to receive the treatment instead of receiving it at home and the necessary recovery period, this process took around two to three hours a fortnight. This worked out as the same amount of time out of my week as I needed for injections.
16. Doctor Webster ensured there were stocks in the Royal Berkshire Hospital in Reading and in 1994 I began having fortnightly infusions in the day ward. The process involved me being hooked up to two bottles of around half the size of a regular bottle of water and contained a clear liquid that looked more like saline than blood.
17. This routine continued until in 1995 when I received a letter from the Royal Free Hospital informing me that I could no longer have these infusions. The letter was just an A5 piece of paper and offered no explanation as to why the infusions must stop, nor any details as to what I should do in the alternative. Nobody from the hospital called me or contacted me to explain this decision further, in any way.
18. I took the letter to my local GP who said he had never seen anything like this and that he did not know how to interpret it. He said it read like a miracle had happened and I would no longer need any other treatments. He said I was the first person he had seen with a letter like that but he also said that he would wait on information from the blood specialists as to how they would treat me going forward.
19. As I was concerned at my lack of treatment, I called and wrote to the doctors at the Royal Free Hospital to get an explanation as to why my infusions had stopped. I also asked if I could begin taking the injections of gamma globulin I had previously taken prior to beginning of the trial of infusions. I was told I could not have the injections as the antibodies in my

body would fight the injections rather than allow them to help. I never got the chance to ask Doctor Webster why my infusions were stopped. After that, it went very quiet, very dead, and apart from attending hospitals for tests, I was no longer contacted by my doctors.

20. After three months of not having the infusions, I began to feel awful. I could feel my health rapidly deteriorate again, back down to 50%. I exhibit a letter dated 25 April 1995 that I received from Doctor Webster responding to my phone calls and confirming that I had been infected with HCV [WITN0549/002]. He also recommended that I contact Professor Dusheiko, a liver specialist. I was very worried and took this letter to my GP, but he said there was nothing he could do at that time to alleviate it; my body just had to fight it.
21. I also exhibit a letter dated 18 July 1996 from Professor Dusheiko containing the results of a liver biopsy I had had at the Royal Free Hospital around Christmas in 1995 [WITN0549/003]. It said that the liver biopsy appearances were in keeping with HCV infection.
22. I have been asked if I was given adequate information to understand and manage the infection, and although my GP was very helpful I do not think I was given enough information. I was given basic information on cross contamination by unprotected sex or by blood and told how to protect family and people close to me from infection.

Section 3. Other Infections

23. I do not believe that as a result of being given infected blood products I have contracted any infection other than the HCV. I assume that while testing me for HCV or during other blood tests, I was at some point tested for HIV and that the results were negative.

24. After I received the letter telling me I had tested positive for HCV GRO-C
GRO-C To the best of my knowledge, my wife has never been tested for either HCV or HIV.

25. GRO-C

Section 4. Consent

26. I have been asked if I believe that I have ever been treated or tested without my knowledge or consent and the answer is no, I have always consented to the treatments and tests.

27. I do believe that I have been treated without being given sufficient information about the treatments I was to receive. For example, I was never told that the blood used may have been sourced from the United States or India until I was told I was infected with HCV.

Section 5. Impact

28. I think the impact on myself was less than it would have been for others in my position because when you have been ill your entire life, you live longer because you get used to dealing with what life throws at you. You just have to accept it. I just tried to carry on with my life, but there were definitely many days when I got up and went to work when really, for my own wellbeing, I should not have.

29. From the hospitals and medical professionals, I felt there was just a sheer lack of information on what had happened and what I should do. I do not know if that was deliberate, whether they did not know what I should do or whether they did not think I needed to know.

30. As they had told me by letter that I had caught HCV from contaminated blood products, it appeared there was no doubt in their minds as to whether they were at fault. Although, I think in 1996 they were just treading water and trying to gather facts to get a general idea about how people felt about the whole problem. I just had to accept it.
31. By 1996, I had already begun subscribing to the Primary Immunodeficiency Association Newsletter. I believe it was in one of these newsletters that I read about a treatment for HCV being trialled called Interferon. I remember I did not know whether to believe it or not, but I wrote to Professor Dusheiko to ask him if I could try it. Professor Dusheiko said he would put me forward for the treatment but he also said that at that time the drug was not freely available; instead people were selected from different areas via a postcode lottery. My letter therefore ended up on a long list of applicants.
32. I remember calling about the process of my application and speaking on the phone to a very nice lady with a strong accent from Barbados who promised she would put a sticky note on my application and put it on the top of the pile. I believe she did so because in August 1996, I received a letter informing me that I had been accepted onto a six-month course of Interferon.
33. I was given the treatment to take home and then I would inject myself three times a week. This would leave a horrible onion type taste in the mouth and did not leave me feeling good. I felt headaches, stomach aches and I would feel constantly nauseous. I completely lost my appetite and after I had lost a stone, the doctors began giving me additional drugs to bring my appetite back. I still got up and went to work most days as I thought I have to keep going. At that time, I worked in a department where you were required to push yourself a bit too much and I worked there throughout the five months of injections.
34. After five months, I was too unwell to finish the course. One morning I phoned a nurse and asked her if she could find out from Professor

Dusheiko whether I could stop taking the injections. He said I could but first I would need to have some blood tests. The first of these tests returned negative results. Fortunately, the second test found that the medicine had worked and that all I had remaining was a trace of HCV in my blood but that it was no longer active.

35. I have been asked about the impact of being infected with HCV on my professional and private life. I can say that being infected with HCV definitely had an affect on my private life. I had to begin having protected sex and I remembered being unsure whether the infection was something I wanted to tell all of my friends and family about.
36. I did not know how people would react, they might get violent or I could get labelled or victimised for having HCV. I had to tell my GP and dentist and it seemed like everyone began to glove up more than usual. There was definitely a stigma attached to having HCV which I could feel, but what could I do about it, I just had to lump it and live with it.
37. In my last job I was fortunate to have two bosses that understood that I was not a very well man and they agreed with HR that I could take as long as I needed to get better. However, nobody at work knew I had HCV. I do not feel as if having HCV affected my career progression much. At different points I felt disorientated and nauseous at work because of the HCV and the Interferon but I was never pulled up by HR for not doing enough or doing something wrong. I think the company's ethos was to stay positive and if you were negative they would tell you on the day that you were letting the side down.
38. I definitely suffered a financial impact because of having to travel to London to see doctors for treatments and tests. At the beginning my trial of the infusions, I was visiting twice a week, which then decreased to once a fortnight and then once every three weeks. This used to cost me a minimum of £20.00 for each journey and I regularly fell asleep from

tiredness on the train. I would sleep with my hands in my pockets so that people would not rob me. I remember being really scared about that.

Section 6. Treatment/Care/Support

39. I have been asked whether I faced any difficulties or obstacles in accessing treatment; I do not believe that I have. However, I do believe I was fortunate to be selected as part of a postcode lottery for the trial of Interferon and I think that the treatment should have been universally available at that time.
40. I think that because I have been ill with pneumonia and haemoglobinaemia during different periods of my life, the psychological impact of being infected with HCV was not as bad as it may otherwise have been. I do not know if counselling would have helped me but I was never offered any counselling or information on accessing psychological services by hospitals or nurses.

Section 7. Financial Assistance

41. One day, a letter came out of the blue from the Caxton Foundation to say that I may be eligible for a monthly payments designated for victims of HCV infection. I think at the time they were just trying to get a list of people together with the same problem. I joined a list of 2500 people at that time and I do not remember being contacted by Caxton again.
42. I remember John Reid MP announcing the Skipton Fund in Parliament in 2003 and saying this must not continue and money must be set aside to help people as some are dead and others, like me, are walking wounded. Skipton had the same office as Caxton and so I contacted them and made an application. It was not a difficult application but no one from Skipton assisted me with making my application.

43. To my great surprise, in 2005, I received a cheque for £20,000.00 from the Skipton Fund. This was incredibly useful to me at the time. Later, in April 2017, Skipton began making monthly payments of £252.00 to me. This continued until April 2018 when the payments increased to £333.33.
44. My overall experience with Skipton Fund has been positive apart from one instance in November 2017 when I received a letter informing me that I was due to receive another significant lump sum payment. Unfortunately, this turned out to be an administrative error once I followed it up. This caused me financial difficulties as I had ordered a new kitchen expecting to receive the lump sum and then had to take out a loan to pay for it once they told me I would not receive anything.

Section 8. Other Issues

45. After I learnt I had been infected with HCV, my daughter arranged for me to see a solicitor at Clifton Ingram LLP in Reading. Simultaneously, I borrowed two payments of £500.00 from my sister, which I used to get my medical records released. The solicitor established that there was a potential NHS fund available but that it was for haemophiliacs. I paid the solicitor to investigate my eligibility for the fund. He advised me that I had around an 80% chance of failure and that I would need to pay £200 a month to retain a QC to pursue the claim. I decided it would not be worth it as I was already £2000 in arrears. I do not think there was enough interest in what had happened at that time and there were not enough people talking about it.
46. Apart from that I have never been an active campaigner and I have never been involved in any group litigation.
47. I hope this Inquiry establishes whether there was really someone at the top responsible for the decision to use potentially contaminated products that is to blame. I would like to know if there was a deliberate ploy to cover up what happened and not tell the public what happened. I think in my case,

my already existing health problems probably helped them cover up what happened.

48. I would like to know if there has been any internal review into what happened. If so, the facts of what happened should have been released and it should be admitted that someone got it wrong. In my case, it seemed that a single professor led most of the team treating me.

49. I would just like to know the truth for everyone's sake. I would like to see that through this Inquiry everything has been looked at and there are processes in place to ensure this really happens.

Statement of Truth

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

Signed

GRO-C: D R Wilks

Dated

12/01/19