

Witness Name: Linda Johnson

Statement No.: WITN3421001

Exhibits: **WITN3421002 - 005**

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LINDA JOHNSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7 August 2019.

I, Linda Johnson, will say as follows: -

Section 1. Introduction

1. My name is Linda Johnson. My date of birth is GRO-C 1951 and my address is known to the Inquiry. I am married and I live with my husband, Mike, in GRO-C. We have a history of renovating properties and dealing in antiques.
2. I intend to speak about my infection with Hepatitis C ("HCV") by blood transfusion. I underwent a series of operations in the period 1973 to 1983 and I believe I received infected blood during one of these operations, most likely a hysterectomy in 1973. In particular, I will speak about the nature of my illness, the treatment I received and the impact it had on my life.

3. 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

4. I gave birth to my daughter, Simone, at St Mary's Hospital in 1971. Following this, I had an infection which caused me pain in my stomach, but it went undiagnosed for 2 years. I was prescribed Valium by my doctor and I was told it was nothing serious. By the time it was diagnosed by laparoscopy, I had to undergo a hysterectomy in June 1974 at St Stephen's Hospital in Fulham. I was in hospital for 10 days following the operation. My medical notes from this operation are missing.
5. Over the next 10 years I had several more operations including a laparotomy, surgery on ovarian cysts, and eventually ovary removal, first on the right ovary and then the left, all at St Stephen's. These were major operations with painful recoveries. It was an extremely difficult period of my life. I was not warned about the possibility of blood transfusion before any of these operations, nor of the risk of infected blood. I attach a letter which provides an overview of the operations I underwent as **WITN3421002**.
6. I have a letter from 1984 which states that my liver function tests are still abnormal. I attach a copy of this letter as **WITN3421003**. Therefore, I must have undergone liver tests before this. I had a couple of liver biopsies at this time. I was referred to Dr Murray-Lyon, a consultant gastroenterologist with a special interest in livers, for advice. Nothing was diagnosed at the time.
7. In 2001, I went for a private medical assessment in order to obtain a mortgage. They took a blood test. I was then contacted by my own GP in Portsmouth, who had received the results, and they told me I had HCV. I felt fine at the time. I was referred to a consultant at St Mary's

Hospital in Portsmouth. I underwent a liver biopsy and it was confirmed that I had HCV and chronic liver cirrhosis.

8. Following the biopsy, I was wrongly diagnosed with liver cancer. I spent 2 weeks believing I had it. When I went back in they told me this was wrong, I did not have cancer, and the consultant denied that it would have been said at all. There were no apologies for the mistake.
9. In respect of my HCV diagnosis, I was given no proper consultation about the infection or how to manage it. No questions were asked about my lifestyle or how I could have contracted HCV. I was given some pamphlets of information, and that was it. Looking back, I believe this was inadequate.
10. My husband was tested for HCV at the time, and he was clear. They told me that I had to warn any medical professionals or dentists that I had HCV, and to be careful of blood contact.

Section 3. Other Infections

11. To the best of my knowledge, I did not receive any infection other than HCV from infected blood.

Section 4. Consent

12. I do not believe I was ever tested or treated without my knowledge or consent. Nor was I tested or treated for research. I was originally offered HCV treatment in its experimental form but I turned it down at the time.

Section 5. Impact

13. The HCV diagnosis did not change the way I lived my life. I was referred to Southampton for treatment, and I was told the treatment was in its early stages. It was Interferon and Ribavirin. I was told that once I was 60 I would not be able to receive the treatment, and this was because it

was so expensive, they did not want to give it to over 60s. I turned it down because I did not want to take the risk of receiving a treatment which was not yet fully understood. We moved to France for a few years, and whilst I was there, the treatment was often on my mind. Though I was very tired, I felt fine physically, so I did not want to put myself through the horrendous side effects that I had been warned about.

14. We moved back from France in 2006 and I decided to start the treatment because I was nearing 60, and I believed I would not be able to receive it once I was 60. I may not have chosen to undergo treatment had I not held this belief at the time. I also believe I was told the cost of the treatment was in the region of £25,000.
15. I underwent Interferon and Ribavirin treatment at the Royal Derby Hospital. I was given the same warning of side-effects, the possibility of hair loss, fatigue, flu, aches, mild depression and severe depression. I was given a 24 hour phone line to call regarding the side effects, and I phoned it once, but nobody was available to answer. I was told it would be 6 months to a year of treatment.
16. I was told again how expensive the treatment was, and that they did not give it to everyone. There was an underlying feeling that I should be grateful for being eligible for the treatment, that I was one of the lucky ones.
17. I experienced every possible side-effect of treatment. We self-administered the injections three times a week at home, my husband Mike did it for me. After the injection it would be an hour until the side-effects hit me. I would be totally drained, I had no energy at all, I could not move. I would sleep through the night and then maybe be able to move the next day. I could not speak or get my words out properly. I never felt completely normal or got back to being myself. It put our lives on hold. We actually rented a property in GRO-C in order that I could undergo the treatment and be reasonably accessible to the hospital.

18. After 4 or 5 weeks on the treatment, I decided I was going to come off it because the side-effects were too extreme. The next time I went into hospital they weighed me and realised my dosage was too high. They had incorrectly calculated it to begin with. It was reduced and I stayed on the treatment.
19. Even after my dose had been reduced, the side-effects were still severe. They did regular blood tests during the course of treatment, and when I had been on it for 11 weeks, they tested me and told me I was clear of HCV. They were surprised the treatment had been successful so quickly. In their experience a patient had never cleared HCV in such a short time. I signed a paper giving permission for them to include my case in a medical journal.
20. That blood test was the end of it, they said there were no further tests they had to do. They told me that one cell left in the body can make the infection come back, but I have not been given any check-ups or tests since 2004. I do not know what condition my liver is in today.
21. Even today I wish I had never had the treatment. I had to be talked into it at the time. If I had realised how bad it was going to be, how much it would change my life, I would not have done it. Suicidal depression was not something I wanted. My hair never grew back properly, it is weak and brittle and still falls out. I have psoriasis. I have memory problems which I did not have before treatment. My energy levels never completely returned to normal. I get frustrated when there are things I cannot do.
22. I only told close friends about my HCV, because of the stigma attached to HCV. It was so embarrassing, even to tell them. HCV was a dirty disease. Most people still do not understand today what HCV is, they assume you are an alcoholic or drug taker. When I told my mother she assumed I drank too much because of the liver connection. I was always embarrassed when I had to tell new doctors about it. Luckily, I did not lose any friends as a result of my infection.

23. I am so lucky to have had Mike there through everything. He has been so supportive, he has always helped me, and came to all my appointments. I do not know what I would have done without him.

Section 6. Treatment/Care/Support

24. I did not face any difficulties obtaining treatment for my HCV.

25. I was not offered any counselling or psychological support following my HCV diagnosis, or following my treatment. The treatment was so disruptive and I was severely depressed. I do believe I should have been offered more support.

Section 7. Financial Assistance

26. After I had undergone treatment, the hospital gave us details in order to apply to the Skipton fund. My first application was rejected in 2008. We appealed this decision. I attach a copy of the letter of appeal which I submitted in May 2009 as **WITN3421004**. A doctor in Derby wrote a supporting statement for me at this time. I attach a copy of this statement as **WITN3421005**.

27. Despite the statement of support which outlined why the doctor believed that the source of HCV infection was blood transfusion during one of my operations, my appeal to the Skipton fund was rejected. They claimed there was a lack of evidence. I believe the threshold for obtaining assistance from the Skipton fund was unfairly high.

Section 8. Other Issues

28. I want the Inquiry to achieve recognition for what went on and how the system has treated people, and tried to hide things. I believe evidence has been hidden. My missing medical records from the hysterectomy are

the reason I was unable to obtain any financial assistance. I feel it is not right. Somebody should be held accountable for this.

29. I have lost all trust in doctors and the medical profession as a result of my experience. Even today I am afraid to go back and have my liver tested.

Statement of Truth

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

Signed GRO-C

Dated 12th October 2019

