

Witness Name: Suzanne Jones

Statement No.: WITN0017/001

Exhibits: WITN0017/002-4

Dated: 20/12/2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUZANNE JONES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 November 2018.

I, Suzanne Jones, will say as follows: -

1. Introduction

1. My name is Suzanne Jones. My date of birth is GRO-C 1966 and my address is known to the Inquiry. I am currently working part time in the Pathology Unit at my local NHS Hospital in Basildon, the same hospital that infected me. I have always wanted to work in a hospital. I work as a Medical Laboratory Assistant and have worked there for over 11 years.

2. I intend to speak about my infection with the Hepatitis C Virus (HCV), which I contracted as a result of an infected blood transfusion during my Scoliosis Operation.

3. I intend to speak about the nature of my illness, how the illness affected me, the treatment received and the overwhelming impact it has had on my family's life, particularly, my mother and father and mine.

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.

2. How Infected

5. I was infected with HCV on 27 February 1984 at Basildon Hospital in Essex, where I received a blood transfusion following my Scoliosis operation.

6. I was diagnosed with Scoliosis at the age of 9. From the age of 10 I was in a brace for 23 hours a day. At the age of 15, I concluded that I did not want to wear the brace anymore as it made me feel self-conscious. A year later I went to the hospital, the doctors said they were worried as my spine was curving and squashing my internal organs. I had to undergo surgery in order to correct my spine. The operation was a great success. My spine had straightened and I no longer had the problems I experienced before.

7. Almost ten years later, I wanted to give something back to the NHS after the success of my operation. On 10 June 1993, I went to give blood. Three months later I received a letter addressed to me dated: 4 August 1993 from the National Blood Transfusion Service, [WITN0017/002]. The letter informed me that I *'should not be frightened or worried by this letter, which has NOTHING to do with the AIDS Virus'*. The letter did state that I had been infected with a virus known as 'Hepatitis C' (HCV). This made me worried so I visited my General Practitioner (GP1) at the time. He told me not to be worried, that it was nothing to worry about. He told me that we should arrange another test in six months and that he would closely monitor me.

8. I went home that day and was frightened; I could not leave it six months. I went back to my General Practitioners surgery and saw a different doctor (GP2). He said he would refer me to the Haematology Unit in Basildon for some answers. I did not hear anything for weeks, then months. I went back to see if GP2 had heard anything. He had not. He said that he had referred me to the Haematology Unit and they ignored him, he was very annoyed at this.

9. I was then referred to the Royal Free Hospital (RFH), Hampstead, London. I received an appointment two weeks later. When I got to RFH a woman asked me if I used needles, or if I do drugs or have tattoos. I do not; she went on to say that I must have got HCV somehow. I would like to say at this point that I have never smoked, taken drugs, had any tattoos or ears pierced or any other part of my anatomy. The letter from the National Blood Transfusion Service told me that '*occasionally the virus can be passed on through blood transfusion*', [WITN0017/002]. Between 27 February 1984 and 4 August 1993 the scoliosis operation was the only blood transfusion I received. I believe the infection must have come from this.

10. Later, Professor Dusheiko at RFH saw me. He was extremely supportive; he wanted to do a liver biopsy and conducted some blood tests. The tests showed that I was HCV positive. He further mentioned to me that there was a drug trial for a drug called Interferon and that it could help clear the virus. The biopsy showed that I had no liver damage, just liver inflammation. This cleared the way to take part in the drug trial. The drug was so new that it took a year to start the trial; we had to constantly keep talking about my start date. Finally, I agreed to the start date on my mum's 60th birthday, on GRO-C 1995.

11. The trial entailed three groups. People who were injected once a week, twice a week or three times per week. I was put into the group who had the injections three times a week. The doctors told me the drug can make you feel very ill upon the first injection, for this reason I was told I had to stay overnight and that I had to go to the RFH every week for nine weeks for blood tests, to see if the HCV has cleared. I lasted 18 months.

12. On the third week, I received some bad news from my liver research nurse. She told me that the American company funding the drug trial had pulled out. I was shocked to find this out; I was never told that an American company was funding the trial. The trial continued regardless and I was funded my travel fares for the first three weeks. After this, I had to pay for my own travel to RFH, the cost of which was £25-30 per trip. This was a lot in

those days. I had to get early trains and rely on my mum and dad's generosity.

13. I continued the injections. After some time they started to make me really ill. In March 1996, I received a phone call from the doctors telling me I had to go to the emergency clinic immediately. I was told that I had developed an underactive thyroid. This was strange to me, as I had never had thyroid problems before. The Interferon had damaged my thyroid, I was told to stop the trial because of this.

14. In September 1996, I restarted the trial. I was now on Levothyroxine for my thyroid. What I did not know at this time was that I was put on Interferon and Ribavirin, it was only from reading the prescription that I found out. I was not asked and only became aware of this at a later stage. I immediately started to feel unwell. I had headaches, joint pains, fatigue and change of personality. I was sweating and still continued to travel for regular blood tests once a month. I continued having my injection three times a week.

15. During Christmas in 1996, I sat in my room and started crying. I just sat on my bed crying. My mum asked if I liked the new stereo I had received as a present and I carried on crying. My body, arms, legs, chest, back and my face were covered in a red rash. I also had vaginal bleeding; I knew it was not my period. I discussed my problems with my mum, she advised me not to take any more injections until I had spoken to Professor Dusheiko.

16. I went back to the RFH and saw Professor Dusheiko. He did throat swabs and meningitis tests and told me not to take any more injections until we received the results. After a few days we received the results, they concluded that I didn't have meningitis and that it was just a reaction to the injections. I went back to work in January 1997.

17. I restarted the injections in March 1997. I had an Aspartate Aminotransferase (AST) and Alanine Aminotransferase (ALT) tests to see how active my HCV was. It had come down to 9 and 11 from 59-61. This was

good. Due to the results, I asked to go back on the injections. I wanted to see whether I could clear the virus for good. Once I started the injections, I immediately fell ill again. I felt depressed; I would come home from work and shut myself in my room. I would not eat or talk, I would just go to bed. I would take all of my emotions out on my family really.

18. In June 1997 Professor Dusheiko told me to stop the injections. He said I had no quality of life. I had no more injections after that. My injections ran from 22 November 1995 to June 1997 with some breaks in between. Once I stopped, I kept going for AST and ALT tests. My levels had reduced to 7 and 9. I received a letter dated 27 August 1997, the letter told me I was clear of HCV and told me I would be monitored for 10 years.

19. I felt as though I wanted to give back to the NHS again. I wanted to donate blood. However, RFH told me although I had cleared the virus, it would still lay dormant in my body, they told me that if I donated blood again it could kill somebody. I can never carry a donor card. I can never donate blood again. This made me feel resentful, I thought I had been cured but I hadn't. They built me up to believe that I did not have the virus. People often tell me I should become a donor but I can't, I have to tell them the reason and it brings back all of my emotions. I feel labelled; I feel I have always been labelled. It is not easy to discuss with people, it is easier to not say anything.

20. In 2007, after years of being monitored I was still considered HCV free. I was discharged from RFH back to my GP.

21. The process of obtaining medical records was good for me. I wrote to the hospital and they gave me various documents on 24 March 2005. The cost was £16.24.

22. As stated above, the information provided to me was in the form of a letter from the National Blood Transfusion Service, dated 4 August 1994, [WITN0017/002]. The information given to me was conflicting and caused me quite a lot of anxiety. On the one hand I was being told by the Transfusion

Service that I was not a risk to anyone, on the other, the Haematology Unit at RFH was telling me that HCV can be spread through infection. I was told to wash things in boiling water and keep my toothbrushes separate; I hated the way that this made me feel.

23. I feel that I was not given adequate information to understand the infection. I was required to do all of the work to find out any information; I had to visit doctors and hospitals to improve my own knowledge. I am extremely angry that I was told three months later from the date I donated blood to the time I found out I had HCV. I do not know why they waited so long, I feel that I should have been told earlier. They should have told me after a couple of weeks. I feel that the way in which the results were communicated to me was very insensitive. This should not have been done in a letter; the letter upset me. I feel it should have been face to face. It was very frightening to receive a letter like that; I kept reading that it had nothing to do with the AIDS virus and could not shake that sentence from my mind. I could not process the information that was being given to me. I am upset that I was given no referral process, I was just told to visit my GP, which was not very helpful.

24. I was given some information about the risks of my HCV being spread: I was told to wear condoms in sexual relationships as it can be spread through bodily fluid and blood to blood contact. I was also told not to share razors and to be careful with toothbrushes.

3. Other Infections

25. To my knowledge I have only contracted HCV as a result of contaminated blood. As a consequence, my general health has deteriorated. I have thyroid problems, fatigue, headaches and joint pains. My symptoms were wrongly described as 'yuppie flu'.

4. Consent

26. I have been asked if I believe that I have ever been tested or treated without my knowledge or consent, the answer to that is: I have given consent but without my full knowledge.

27. I believe that I was not given sufficient information about the side effects of the treatment I received. The side effects were horrible, they made me feel fatigued and have constant pain. As previously stated, I was not told that I had been put on Ribavirin; it was only through me reading my prescription that I found out. In hindsight, I felt like I was being experimented on but I can't say one way or the other, I was not told how toxic the drugs were. At one point, I was given a leaflet that stated the drugs might affect my thyroid. However, months later the leaflet had changed information stating that the treatment will affect your thyroid. This information was changed after I had been infected. This made me feel as if I was a guinea pig and part of an experiment, I am sure I was put in the third group as I only had liver inflammation. I had attended a HCV patients meeting and found out other people had died as a result of the treatment they were receiving; this made me extremely upset.

28. I believe that I was used for the purpose of research. An American Pharmaceutical company funded the treatment. They later pulled the funding when they found that the results were not conclusive in clearing the virus.

5. Impact

29. The mental and physical effects of being infected with HCV are profound. I feel constantly fatigued. I suffer from bouts of physical pain such as severe headaches and joint pains. I have had thyroid problems as a direct result of the treatment I have received. The stress has caused me to come out in sores, which has been a problem for years; since the HCV was confirmed. After the drug trial of interferon and ribavirin, I started to feel really fatigued and ill, I feel that this is the starting point of my illness. Mentally, I was really low and depressed all the time. If I caught a cold I wouldn't want to go near anyone, I am constantly paranoid that I am going to get a cold. It is impossible to avoid because of the medication that I take. I pick up infections very easily,

I insist on getting up and moving seats if someone coughs on public transport for fear of getting a cold. This has had a big effect on me, I no longer go out like I used to. I am frightened and paranoid of infection. After the drug trial I became really withdrawn and fatigued and now my social life is non-existent.

30. Since completing the Interferon and Ribavirin treatments I have suffered from numerous health problems. In 2006 I had pains in my legs and groin, which resulted in a laparoscopy to establish what was wrong. The doctors were checking for a hernia. After the operation I was getting bad chest pains so I had X-rays and CT scans, these admitted me to hospital. The doctors thought that they would not discover anything but they found blood clots on both of my lungs: a large clot on my left lung and small clots on both lungs. They gave me heparin injections and warfarin tablets to disperse the clots; this is life long medication.

31. After my operation I was handed a form that said I had lupus anticoagulant demonstrated. I was confused and did not know what this meant as the doctor had left me. I broke down in tears. Nobody explained anything to me, I contacted the lupus trust and they told me I could go to the London Lupus Centre. I took my blood test results there. The doctor at the Lupus Centre told me it was Antiphospholipid Syndrome, which is otherwise known as 'sticky blood', it means that my blood has a tendency to clot without medication. It is also known as Hughes Syndrome, named after Graham Hughes. The doctors told me they could not link the syndrome to having HCV but they could not be sure.

32. However, I am in full belief that my problems have arisen from my immune system being destroyed trying to fight off the HCV. I further believe that my problems are a direct result of the treatment that I was placed on when trying to clear the virus. I feel that my immune system was severely compromised. As a result I am more susceptible to getting viruses and infections. Since the treatment I have had various problems with my breathing and do not sleep at all. I am awake all night, every night, tired throughout the day. I also suffer

from a stress related skin condition called Nodular Prurigo. I feel this condition stems from the stress and emotional strain of receiving my transfusion letter.

33. I have been asked if I have faced any difficulties or obstacles in obtaining treatment. Although I have not faced any problems, I feel that when I declare my HCV to medical institutions their reaction is quite extreme, especially as I have been clear for 15 years. When I had my knee operation I was told the theatre staff had to protect themselves. Three different people had asked me on three different occasions if I was HCV positive. This made me feel stressed, awkward and uncomfortable. It would have been useful to have a medical card in this situation, as doctors kept pestering me and gave me little privacy. They would talk openly about my infection, without drawing the curtains shut. Members of the public could hear our whole conversation making me extremely paranoid. I feel that I have had operations delayed because of my HCV infection. It makes me feel dirty. I can't get past the stigma; although I have cleared the virus I am constantly reminded that I still have it.

34. In comparison I would like to point out that I have had a very positive experience with the dentist. I let the dentist know of my infection the first time I visited once I was diagnosed and he thanked me. He told me he would put in his notes and that it was fine. I must admit that in the back of my mind, I was always fearful of visiting the dentist because of the stigma surrounding HCV. It prevented me from seeking dental care at an earlier stage. However, this experience made me feel relieved and I was appreciative of the dentist's candour and acknowledgement.

35. Being infected with HCV has made me withdraw myself more and more. It has been the centre of my attention; it has taken over my life. All I think about are my medical problems; I feel that this has been a direct result of the HCV treatment. I do not go out and see friends. I mainly stay at home. I do go on holiday with my mum and dad but this causes problems in itself, I think about the stigma of a 52 year old going away with their mum and dad. I feel as

though it has taken my life away and that I have little control; hospital appointments dictate my life. I have felt like this since I have been diagnosed.

36. There is a definite stigma attached to being infected with HCV. As previously mentioned, I have experienced it first hand over the years. I am lucky to have had such supportive parents.

37. The HCV has totally ruined my parents' life and mine; they have not had a retirement because of my hospital appointments. I still have to go hospital because of my thyroid problems, which was caused by the drug treatment. It has affected my chance of a family. If I hadn't been infected I might have had children, I might have been married, or own my own home. Yet my life has been all about hospital appointments. I often wonder what life would have been like. My brother has a son and daughter: my nephew and niece. This triggers a thought process that they are not going to get cousins. I feel guilty, even though it's not my fault.

38. In relation to how my infection has impacted my education, I have managed to complete a course at Basildon Hospital in medical terminology. However, this was extremely difficult and I really struggled to get through it. Now I suffer from too much fatigue and memory loss to complete any further courses. I feel as if it is all because of my infection and the consequential treatment. This makes me feel resentful; that I can no longer further my education as I wish.

39. Since I was diagnosed with HCV, my work life has been severely impacted. I have had to work part time for the majority of my career since my treatment, this is mainly due to fatigue. My GP has told me that I cannot work full time and can only work a maximum of 22.5 hours per week. This drop of hours equals a loss of income. I was really struggling due to this; I had to rely on my mum and dad, I kept telling them I will pay them next month. This put me under massive stress. Before my infection, I was always able to work without problems; my career path has now come to a complete halt. I have no

chance of promotion and I can't apply for full time jobs, simply because of my fatigue. I am not fit enough and my health has dictated my career path.

40. One Boxing day in 2013, I had come home exhausted after work. I had worked Christmas Eve, Christmas Day and Boxing Day. I had collapsed at 13:30pm due to the exhaustion and stress I was under. I am forced to work these shifts as I can't work full time and I need the money.

41. The financial effects after my infection have been extremely negative. I have had to rely on my mum and dad for a lot. An expert, my sister in law, who is a benefits fraud officer, has assisted me. She told me to apply for government grants. Had I not been successful in those grants and the support of my mum and dad I would be struggling, bordering poverty. I am off work at present because of my two operations; this has caused me to be on half pay, which has had a dramatic effect on my financial situation.

6. Treatment/Care/Support

42. I remember a time in which I had to appear before a tribunal at Southend. I am registered disabled for my two knee replacements and my need for care. Initially, I was turned down for Personal Independence Payment (PIP). I appealed at a tribunal in Romford, held by a judge. The judge went through my medical history and awarded me the care part of PIP. This was because my mum had to cook my meals, help me get dressed and generally look after me. The judge commented on my HCV and asked my mum to comment. My mum said how difficult it had been with the HCV and had mentioned that previously I had always worked full time. She told the judge about my Scoliosis operation, which was a success and that 10 years later I was told I had HCV, which completely ruined my life. The judge was horrified and asked my mum if we had thought about suing the surgeon. We had not. Being awarded the care part of PIP allowed me to receive more money.

43. I have been offered psychological support on various occasions but I have always respectfully declined. I am too worried about the stigma attached to

HCV and I worry about what people will think. During my Interview for the Inquiry, I was informed about the support mechanism provided by the British Red Cross. I was given the relevant telephone numbers to call. I feel more inclined to seek this support, as I would be more comfortable speaking to somebody who knows about the Inquiry.

7. Financial Assistance

44. On 26 January 2003 the Department of Health wrote to me. In the letter they told me about an ex-gratia scheme being launched called The Skipton Fund. I was then told how to apply and sent off the various forms needed for the application. I was angered to find out that the first time I applied my forms had been lost. The Fund had no record, even though I had proof of postage. They sent me another set of forms; I completed these and returned them. This time the Fund received my information. Later, I received a letter stating that they needed further information from my GP.

45. I received the first £20,000 on 19 April 2005. It was a conditional offer. If I accept the £20,000, I could not apply for any further payments in connection to being infected with HCV. This caused me many problems, if I did not accept the agreement then I would not receive any money. This made me terribly angry, they were holding me to ransom. I did not know what to do. I needed the money, so I had to accept it.

46. I received a further payment from Skipton on 19 December 2016 for £3,500. From 20 April 2017, I have received monthly payments of £250. I receive fuel allowance of £500. I had also applied to Caxton; I filled out further forms in order to top up my wages. I got turned down for this due to my household income; it topped me over the threshold. I feel this is very unfair, my parents are pensioners and we do not have a lot of money. I received nothing from Caxton; they simply said they could not help me.

47. I received a letter from English Infected Blood Support Scheme (EIBSS) on 20 October 2017. They told me that they were replacing all the other

schemes. I had to fill out a new set of forms and state that I was happy to transfer onto this scheme.

48. I can wholeheartedly say that the money I received was not enough. The process was stressful, especially seeing my doctors and getting them to fill out the forms. This process was at their leisure and took longer than I had hoped. I had to pay £20 per form, which for part time work was a lot, especially as I had to fill out multiple forms. I am not treated as my own person in being infected and I feel that I am penalised, as I don't have my own house. This is distressing, as I can't live on my own as due to my health issues. I cannot work full time and thus, I cannot afford my own place. This is so very unfair; I am frustrated because I can't get anywhere. I am no longer independent so I feel isolated. I now feel I will never leave home. My dad is 87 GRO-C and he needs respite care. I worry about my mum and her health. I worry about where we are going to be in 10 years time. I worry about what will happen in the future. I need to look after them. I have to liaise with social workers about the care of my parents; this has caused me more and more stress.

8. Other Issues

49. I have been asked to provide a full list of the medical institutions that I have attended for clarity:

- Basildon Hospital, Essex (Scoliosis, this is where I was infected)
- Royal Free Hospital, Hampstead, London
- London Bridge Hospital, (Hughes syndrome, Private Hospital)
- Royal London Hospital, (Immunology referral)
- St. Georges Hospital, Tooting
- Orsett Hospital, Essex

50. I would also like to point the inquiry to a letter dated 24 February 1984, **[WITN0017/003]**. This letter shows a record of my blood transfusion: hospital number 269916. The document relates to various numbers

(16/17/18/19/20/21) and gives various blood pack numbers, of which expire on the 9 - 13 March 2003. This letter coincides with my scoliosis operation.

51. I would like to further submit a letter that I received from my local MP, Andrew Mackinlay. In and around the beginning of 1995 I made contact with my local MP, Andrew Mackinlay. He was the MP for Thurrock and I made him aware of the history of my HCV infection. Over the years I have engaged in a number of written letters, he has now retired and was replaced by Jackie Doyle Price MP, in which I am also in written communication with. In particular, I wish to draw to the inquiry's attention a letter from Mr. Mackinlay, dated 7 March 1995, addressed to me. Attached to that letter dated 6 March 1995 is an official headed notepaper from the department of Health, Richmond House, 79, Whitehall London, SW1A 2NS, signed by Tom Sackville. There are 7 paragraphs, I draw particular attention to paragraph number 5, which states: *'the government does not accept, however, that there has been any negligence and we have no plans to make payments to such patients. On the more general issue of compensation, the government has never accepted the case for a no fault scheme of compensation for medical accidents. It is unfair to others and still requires proof of causation, which is often difficult to establish. Every individual case where a medical accident has occurred is a personal tragedy for both the individual concerned to their family. If the NHS is proved negligent in court, it accepts liability to pay damages'*, [WITN0017/004].

52. My response to this letter is that somebody has to accept responsibility, the infected blood has affected so many people some of who are no longer with us and can't shout for justice. On a personal level I feel that this has ruined my life physically, emotionally and financially and I don't know what the future holds for me.

53. In and around April 1996 (exact date unknown), GRO-D my orthopaedic surgeon, contacted me. He rang me and asked whether I would be willing to participate in a BBC panorama programme, on people infected with HCV. He later wrote to me again on 7 May 1996. I agreed to appear on

the programme, with the condition that nothing negative was said about **GRO-D** **GRO-D** or Basildon hospital; I was still having treatment there. Later, the BBC contacted me to discuss going on the programme. However, once I made them aware of my conditions they were no longer interested. I never appeared on the programme.

54. In relation to the inquiry I do have some concerns:

- 1) I feel that the government will try to cover their own backs – such as in another national exposé by the BBC where they discovered wrongdoing. I was made aware that people were told what to say, whether this was accurate information or not.
- 2) My fear is that in this inquiry the same attitudes and behaviours will be demonstrated.

55. I attended the community engagement meetings in London before the preliminary hearings. I want to know why the blood continued to be used and who was responsible. I just want answers. I want to know why it happened; I am wrapped up in the inquiry. Going through the statement is bringing it all back. I am emotional and anxious. We need some answers for those who are not here. If we can do something for them, that will be justice.

Statement of Truth

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

Signed

GRO-C

Dated

20/12/18

