

ANONYMOUS

Witness Name: Jacqueline [GRO-B]

Statement No.: WITN0508001

Exhibits: WITN0508002 - 3

Dated: 28/11/18

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JACQUELINE

[GRO-B]

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 9 September 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Jacqueline [GRO-B], will say as follows:

Section 1. Introduction

1. My name is Jacqueline [GRO-B]. My date of birth and my address are known to the Inquiry.
2. I work part-time [GRO-B] at Heathrow Airport. I am married and I have two children.
3. I intend to speak about my life and how I became infected with Hepatitis C virus (HCV), genotype 1B.
4. In particular, I will go into details on how the contamination has impacted on my general health and wellbeing and how the illness has affected my relationship with my husband and my children.
5. I have been asked if I am currently legally represented, the answer is no.
6. I am content for my statement to be taken by the investigators from the Inquiry. My husband also assists me, as sometimes my memory is not very good especially with dates and names.

ANONYMOUS

Section 2. How Infected

7. I was infected with Hepatitis C through a blood transfusion I received at West Middlesex Hospital, Isleworth as a result of a severe bleed after my son's birth.
8. I naturally gave birth to my son on 1985. I remember that shortly after my husband left to go back to work, I started to feel incredibly weak and faint. All of a sudden there were doctors everywhere around me; I had a haemorrhage.
9. The doctors told me they were going to give me a transfusion but did not end up giving it to me on that day. They were hoping that I would not need the transfusion and that I would replace the blood that I lost naturally.
10. Without any explanation I then received a blood transfusion three days later, on 1985.
11. On the medical form the doctor filled in, there is clearly written that the blood transfusion was requested on the (WITN0508002) even though I actually received it only three days later. I find this quite weird.
12. I don't know why the form has been filled in that way. I was not given any information or advice prior to the transfusion, especially in relation to the risks of being exposed to infection. After they gave me the blood I started to feel better and I went home.
13. Around 1987, when the media started to talk about HIV and blood transfusions, I went to my doctor and I asked him if I might be infected. He laughed and said that if I wanted he would test me, but he only ended up doing a standard blood test.
14. I think he did it just to keep me quiet, I do not think he did it because he knew about the potential risk of infection or because he wanted to avoid the truth. The test he did was a generic one so the results were fine and nothing was wrong. My life went on normally.
15. In 2013, I requested my GP to do some more specific tests on me because, despite all the other doctors I met told me that I was just depressed, I knew that something else was wrong. My GP was very good and he agreed that we should test for everything, including Hepatitis C.

ANONYMOUS

16. On 19 December 2013, I got a number of messages from the doctor's surgery telling me to call back about the hepatitis test. After each message I would call them but reception would tell me that I did not need to come in and that they did not know why I was being told to call. Apparently the locum doctors working at that time did not have access to my results so they kept telling reception that there was nothing to worry about. Finally, the head of the practice rang me and told me that he needed to see me urgently. He booked me in for an appointment for that afternoon. It was the only appointment my husband could not make. He always accompanied me everywhere, but not that day. This is how I found out that I was infected. The doctor told me that my test had come back positive for Hepatitis C.
17. I was told that 29 years after I had a blood transfusion, I was infected with HCV (genotype 1B). For almost 30 years I silently had to have the infection in my body just because nobody asked the right questions or bothered to understand what was wrong with me and my health.
18. The GP also asked me if I had used drugs or had any tattoos in the past. I told him I had never done drugs. I had never even smoked before, but that I had a small tattoo. He was quite dismissive until he asked me if I had ever had a transfusion and I told him that I indeed had one after my son's birth. His manner changed instantly, he became extremely kind and polite. I think he felt sorry for me and he felt bad that I was not diagnosed earlier.
19. The doctor was very honest with me and told me that he did not know much about the virus, so he referred me to a specialist at Frimley Park Hospital. I remember I was devastated because I thought I had HIV.
20. I went home and I search the Internet for everything about Hepatitis C. I have been confused and worried for three months, until I met my specialist nurse at Frimley Park Hospital. She told me about the risks of Hepatitis C and gave me the treatment options. I really cannot fault her, she was fantastic.
21. I do not believe I was given enough information when I was diagnosed, however, the information I was given by my specialist nurse at Frimley Park was great. They did a lot of tests and explained me everything about the results. I could not have had better care, particularly from my specialist nurse.

ANONYMOUS

22. It was not until my appointment at Frimley Park that the risk of others being infected as a result of my hepatitis C infection was explained to me. That was truly horrible, the idea that I could have infected my daughter (who was also pregnant at that time) was devastating. Luckily, my family has been tested and they are all ok.

Section 3. Other Infections

23. As far as I am aware, I did not contract any other infections or viruses from the blood I received during the transfusion.

Section 4. Consent

24. I do not believe I was tested for any infections or viruses without my knowledge.
25. I did, however, get the feeling that the doctors were using me for research purposes during my second treatment for Hepatitis C. I was put on a new treatment called Harvoni and my hands literally stripped themselves red raw of skin (**WITN0508003**). Apparently I was the first person to have that side effect. I felt a bit like a guinea pig on that drug.

Section 5. Impact

26. The mental and physical effects of being infected with hepatitis C were severe.
27. Within a couple of years of the transfusion, I changed completely, I became very moody and I started to lose my temper on a daily basis. I could not handle the children: I never neglected them but I just did not have any patience with them. They were deprived of my love and of my time.
28. The depression was unreal. I went to the doctor to discuss my moods and he told me that I was depressed and that I was grieving my Mum's loss (she died when I was 15 years old). I was very close to her, and the doctor thought I had not grieved her death.
29. In 1987 they put me on anti-depressants and sent me to counselling for six weeks. During those sessions I finally came to terms with Mum's death, I could talk about her without crying. I thought I was ok, that the problem was solved and that I would have now felt much

ANONYMOUS

better. But the depression and the anti-depressants went on for 30 years.

30. For example, I would be driving along and I would just burst into tears for no reason. At one point I thought that I should take my own life. As I tipped my head back to take a load of tablets, I saw a picture of my four grandchildren and I could not do it, they were all looking at me.
31. Physically, I was exhausted. Some mornings I could hardly move, my whole body ached like when you have flu. I kept wishing I would get sick properly so whatever was in my body would come out. It felt like my organs were asleep. More than once, when the pain was really bad, my husband had to help me out of bed. My old GP just told me to have some tonic, and to take gin with it too.
32. I did not have any other medical complications as a result of my infection with Hepatitis C.
33. When I was finally diagnosed, I had to go through two treatments to clear my infection. The first treatment started in October 2014 and went on for six months. I was put on Pegylated interferon 180ug sub cut, Ribavirin 600mg bd and Telaprevir 1,125mg bd. I was told I was cleared of the virus and at first I did feel a lot better but in September 2015 I got up one morning and I remember I told my husband that the hepatitis C had come back. I had it in me for 29 years so I knew it was back.
34. I had more tests and I was right: Hepatitis C was still in my body. I started the second treatment in February 2016 – it was a stronger treatment but it went on for for three months only. I was put on Harvoni (Sofosbuvir 400mg/Ledipasvir 90mg) and Ribovirin 600mg.
35. For my second treatment, my specialist nurse had to sit before a council of doctors to argue my case and there was a delay in receiving the treatment. That was the only difficulty I experienced in accessing treatments: I think money was the main reason, that's why it took them so long to approve it.
36. I do not believe there were any treatments available at the time that ought to have been given to me but were not.
37. The mental and physical effects of my treatments were devastating. The first treatment lasted for 6 months and it was chaos. I remember one night in particular when I completely flipped. My husband went

ANONYMOUS

out with some friends while I stayed at home. Then all of a sudden something changed. I called him and started screaming at him, asking why he had left me all alone. I did not stop shouting and screaming until the Monday.

38. We went to see my specialist nurse and she insisted that it was just the drugs and that I should finish the course. Physically, I was exhausted; I would not wash, clean my hair or get dressed. I experienced almost every side effect listed for the drugs. I was in hideous pain while going to the bathroom, I was nauseous and ached all over; my sleeping patterns were way out.
39. The side effects of the second treatment were more or less the same as the first treatment, except that during the second treatment as I already mentioned above; my hands literally stripped themselves red raw of skin (**WITN0508003**). Every night I had to put Epaderm Ointment on them (a paraffin based ointment) and wear cotton gloves. The dermatologist from Frimley Park Hospital told me he had never seen anything like that before.
40. In August 2016 I got a call saying that I was all clear of the virus. I just burst into tears. I was crying with happiness. The depression went away once all the drugs were out of my body. I was a different person.
41. I have not had any issues accessing treatment for any other conditions since being diagnosed with Hepatitis C. My dentist was a little taken aback when I first told her about HCV but she never stopped my dental care.
42. Having Hepatitis C had an enormous impact on my personal and family life. I never told my kids that I loved them; I was just so irritable with them. At that time, I felt that I could not handle them because I did not have anyone to guide me. I now realise that it was HCV that was "eating me inside".
43. The infection changed my relationship with my grandchildren too. I used to say to them, "if you see nanny bleeding, do not touch nanny's blood because it is dirty". I used to make them wear gloves in the house if I had a cut or if I was bleeding. We got used to being so careful but it was dreadful.
44. HCV and the treatments had a massive impact on my marriage. We went through utter hell. I completely changed from the woman my

ANONYMOUS

husband first met. If he was not so patient, you would be probably be looking at a woman with a broken marriage.

45. I used to be quite social but I stopped going out when my mood changed because of HCV. I just did not want people around me and I did not want to be around people. It really did wreck 30 odd years of my life. 29 years being infected, and 3 years of treatment.
46. When I was diagnosed, I started to be completely honest with the people I wanted to tell about it. But we kept it within the family and the very close friends only because we did not want to experience any stigma. I do remember that a woman at work, who was tasked with looking out for me, once told me that I must have been an alcoholic to be diagnosed with hepatitis. That was the only real stigma I experienced.
47. By the time I became infected with Hepatitis C I had finished school, so it did not have any educational effects on me. I also was not prevented from anything in my profession. My previous employer was absolutely fantastic. When I found out about my infection and during my treatments, I took quite a bit of time off work and they kept paying me. They didn't ask any questions.
48. One of the effects of the antidepressants they put me on while I was infected was that to cheer me up I would just constantly spend money. I nearly got us evicted and lost us everything because we were in such debt. This was the main financial effect of being infected.
49. My children really suffered as a result of me being infected with hepatitis C. I know that they were deprived of a mum; a loving, caring mum. When I went through my first treatment, my daughter and husband also went through absolute hell too. They tell me that now I am a completely different person.

Section 6. Treatment/Care/Support

50. I did not face any difficulties or obstacles in obtaining treatment, care or support in consequence of being infected with hepatitis C.
51. Neither counselling nor psychological support has ever been offered to me since being diagnosed; I think it would have definitely helped. My specialist nurse was the only support I had. Since I have been given the all clear of hepatitis C, I also have not been given any after care.

ANONYMOUS

Section 7. Financial Assistance

52. I receive financial assistance from the Skipton Fund and I found out about it from my specialist nurse.
53. I have received stage 1 and 2 payments from Skipton. I received £20,000 in August 2014, £50,000 in August or September 2017 together with the winter fuel allowance. I received this second payment because of the cirrhosis of the liver that I developed. I also receive £1,500 per month from Skipton.
54. The application process was easy. I filled the forms in by myself and everything was fine, it was accepted with no problems. I think I just needed to provide evidence that I was infected and that I had a transfusion. I rang the hospital up to ask for my medical records and they sent them to me within a few weeks.
55. There were no preconditions imposed on me to make the application for financial assistance.

Section 8. Other Issues

56. I am expecting the truth from this Inquiry. I want to know why this happened. If the NHS knew that the blood was not clean, why did they carry on using it, knowing that they were putting people's lives at risk? Not only those infected, but also the lives of those around them.
57. I always think that if I did not have that transfusion, then my kids would not have had a mum today so I know I needed that blood. I did not want them to go through what I went through when I lost my mum at 15. But they did not have a proper mum really, that was taken away from me and from them and no money can pay for that.
58. I believe that they should have tested me long before they did, they should have tested every single person who had a transfusion in those years. If they had tested me sooner, my kids might have had a proper life with a loving and caring mum the way that my mum brought me up. That is what hurts the most.
59. I also believe I should have received the treatments for my Hepatitis C sooner; it took almost a year from the diagnosis to the first treatment. Even for the second treatment, there was a delay.

ANONYMOUS

60. I have not been involved in any group litigation, in any other inquiries, investigations or in campaigning in relation to infected blood. I am relieved that someone is finally listening now.

Statement of Truth

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

Signed GRO-B

Dated 28/11/18.