

Witness Name: Imelda Stephenson

Statement No.: WITN4135001

Exhibits: **WITN4135002**

Dated: 9 September 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF IMELDA ELIZABETH STEPHENSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 1 September 2019.

I, Imelda Stephenson, will say as follows: -

Section 1. Introduction

1. My name is Imelda Stephenson. My date of birth is GRO-C 1962 and my home address is known to the Inquiry. I have been married three times. I remain married to my third husband. I have two grown sons, a step-daughter who I regard as my own as well as nine grandchildren. I also have three siblings, two brothers and a sister.
2. I do not currently work due to ongoing health problems, some to do with Hepatitis C and others not. I have previously worked as a visiting care in the community worker and I have also been a mini cab driver, barmaid and cook.
3. I intend to speak about my Hepatitis C (HCV) infection. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it has had on me and my family.

Section 2. How Infected

4. I had a normal pregnancy and delivery with my first son Tim in 1979, I was healthy before and after. My health problems really began in 1983 with my second pregnancy and the delivery of my son Scott.
5. I had a 'show' of blood about six and a half weeks from being full term and was admitted to hospital. I was living in Gloucester at the time so I went to Gloucester Royal Hospital. After having been at the hospital for a few days, I decided to have a bath. I remember moving and all of a sudden, I had a very heavy bleed – I mean a lot of blood coming from my vagina. I immediately called for assistance. When the nurse who came to my aid tried to move my leg I heard a popping like sound and felt something burst.
6. The nurse quickly called for a doctor to come and examine me after which I was rushed to delivery. I heard them saying "we need more blood". I needed an emergency Caesarean section. It was so urgent that I was still awake during the procedure before the anaesthesia had had chance to kick in. My son Scott was delivered six weeks early.
7. When I came around about 18 hours later, I was told that I had lost about six and a half pints of blood. However, apparently after the first pint and half that they gave me, they realised I had reacted to the blood. I was covered in a rash from head to toe, so I was given plasma to replace the rest of the blood I had lost. I was anaemic.
8. I was traumatised by the birth process, I thought I was going to die and was very concerned for my baby because he was premature and had been taken from me and put in an incubator. I did not see him until he was three or four days old.

9. When I first properly saw Scott, I rejected him. I had not had that initial bonding period and was suffering from postnatal depression. However, I do remember the moment while still in hospital, when he was placed on me and I just held him as he fed from me for the first time. I loved him and took care of him from that moment.
10. I suffered from postnatal depression for about four years after Scott's birth. It caused the breakdown of my first marriage. After that, I suffered from depression from time to time. I also suffered from high blood pressure and sporadic stress related asthma.
11. In November 2012, my father passed away. My siblings and I had been very close to our father. He had brought us up as a single parent after our mother had passed away when I was about 14. So my father's death was a very traumatic time in my life. It triggered my depression again as I grieved heavily.
12. During this time my husband and I were living in Crowland, near Peterborough and I was a visiting care in the community worker.
13. Not long after my father's funeral, I was working and driving to Spalding to visit a client. I had been fine earlier when suddenly I started sweating profusely, I was cold, shaking and it felt like the road was coming up towards me.
14. I rang my boss who told me to go home. When I got home I laid in bed for 3 days. My husband was worried so he took me to the doctors for a check-up. This was at Crowland Health Centre which was quite close by.
15. The female GP whose name I cannot recall, took samples to have my bloods tested. I wasn't specifically told what the tests were but I guessed it was for a number of things to try to establish what was wrong with me.

16. An hour later the doctor rang my husband to inform us that there was a problem and my liver and enzyme counts were very high, and that they would need to do another blood test.
17. I received a phone call two days later telling me to come over to see the doctor. The surgery was literally across the road from where we were living at the time. When we got to there, I was told by the same GP that the results showed that I had Hepatitis. They did not know what type of Hepatitis it was, but I had an idea that this was fairly serious. Due to the nature of my work at that time, though I had not been inoculated for Hepatitis B, I had to wear gloves to prevent the risk of infection and I had previously learned about it.
18. I asked the doctor where this could have come from, so she asked if I had ever been an intravenous drug user or had a tattoo or a blood transfusion. I have no tattoos and I have never been a drug user apart from maybe smoking a cannabis cigarette when I was younger. The only possible thing was the blood transfusion I had at the time of my second son's birth.
19. The doctors put me in touch with the hepatology team at Peterborough City Hospital. A week later, the consultant Dr TK Das told me I had Hepatitis C. He explained that it was passed through blood and would rarely be passed on through sexual contact. I was told I would need to be careful if I cut myself, and no sharing of razors or toothbrushes. The doctor also said that ultimately and a worst case prospect is that it was a life threatening virus and I could develop cirrhosis of the liver and even cancer. They advised me not to drink. I hadn't been a drinker for 20 years so that did not matter.

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21. I was assigned a nurse Katherine Barry, who was absolutely amazing. She always kept me informed, and was able to tell if I was having a good or bad day. She would calm me down if I came to them in tears. Even when I moved 18 miles away to Corby, I chose to stay with the team at Peterborough Hospital because of the care I received, my familiarity with the team and them with me.
22. Not long after my diagnosis, the doctors performed a liver biopsy and I had scans which confirmed that I had Hepatitis C, scarring on my liver and fibrosis, but no cirrhosis.
23. I had to wait two and a half years for treatment after that. Before I had treatment, my nurse Katherine discussed it with me and told me that there was a new treatment coming soon and that it might be better to wait for that because it had fewer side effects. However, it turned out that they were only offering the new treatment to people whose cases were more severe than mine, so I had to have the old treatment anyway.
24. In 2016, I was given a three month course of Interferon and Ribavirin. I had to take one Ribavirin tablet a day and inject myself with Interferon once a week, on a Wednesday. I was shown how to do this but it was administered with a type of push button pen, not a hypodermic needle. It was not nice but not difficult either. I will cover the side effects later in this statement.

Section 3. Other Infections

25. I do not believe that I have received any infection other than Hepatitis C as a result of being given infected blood.

Section 4. Consent

26. I do not believe that I have been treated or tested without my knowledge and consent. Just before Scott's birth, even though it was urgent I even had to sign some forms but I was so out of it on Pethidine and gas & air that I do not know what I was signing for. It could have been for the C-section and/or the blood transfusion but I never knew.

Section 5. Impact

27. All my health and fertility problems started to happen after I had that pregnancy with Scott and his subsequent birth. I was fine beforehand. I believe my later fertility problems emanated from that.

28. I had several miscarriages including a late miscarriage at five and a half months pregnant, which tore me apart. It was a girl and I named her Stephanie as I always said if I had a girl I would name her that.

29. It affected a lot of my relationships including my current relationship with my husband. It affected our sexual relationship because I was worried about passing it on. My current husband Paul, and I were briefly estranged for about five months in 2019, which was after I had been cured, but a lot of our problems go back to this.

30. I did not feel any stigma about telling my friends and family about my HCV diagnosis because I was diagnosed more recently so societal attitudes have changed. I told my family and I wasn't bothered about telling people.

31. There was no noticeable difference in the way health professionals treated me, in fact on one occasion, I noticed that a nurse was not wearing gloves when she came to draw my blood. I told her that I had hepatitis C and that she should wear gloves, but she said she's aware and that she was fine since she had no visible cuts on her arm.

32. I received a letter a year ago, which is after I had already been cleared of Hepatitis C, which said that a routine scan showed I had liver cirrhosis. It was a frightening thing to read and I started panicking. I freaked out because I thought I had been cleared but now I was worried that the Hepatitis C was back. I managed to speak to Katherine Barry within about half an hour and she put my mind at rest. She told me to calm down that I had been cleared and the letter was wrong. She said another patient had received a similar letter recently, and the recording of the scan reading was a mistake. I rang my sister and my son after and they too reassured me that the letter couldn't be right.
33. I had to have another scan about a week after to confirm that I was clear of Hepatitis C and I got the results on the same day, confirming that I was clear.

Section 6. Treatment/Care/Support

34. I was living in Peterborough at the time I started receiving Hepatitis C treatment. I had to go get the injection at the hospital the first time. The treatment made me cry all the time, and I couldn't work while receiving treatment. I used to take the injections on Wednesdays because the first time I had received the interferon at the hospital was a Wednesday.
35. The treatment affected me a lot. It increased my depression and it used to make me feel cold. I couldn't carry out daily tasks anymore because I was so fatigued. I usually keep my house immaculate but I couldn't muster the energy to do tasks like cleaning or cooking and I lost interest and didn't care. It even extended to my personal hygiene. I would spend the whole day in pyjamas sleeping all the time.
36. I had to have a test every two weeks during my treatment. When I started, my liver count or viral load started to go down with each test, then there was a blip when it rose, before it finally came down. I have

been told my viral load is now within normal levels. I still have to have yearly blood tests.

37. After I stopped the treatment, it took about a year for the severe side effects to subside. I do still get tired and fatigued from time to time. I believe that my depression over the last 8 years is mainly due to Hepatitis C.

38. I have never been offered counselling specifically for the Hepatitis C diagnosis. I was offered psychological support for my depression around 2018, and I attended but it wasn't for me and did not work out.

Section 7. Financial Assistance

39. My nurse Katherine told me about the Skipton Fund. I applied for financial assistance in March 2015 and sent my application forms to the hospital for support. The process was alright even though they asked for more information which I later sent to them.

40. I received a first stage payment of £20,000 and currently receive a monthly payment of £1558. It was a lot of money so I was in shock at first. I also receive a cold weather allowance and fuel allowance of £500 in around November/December.

41. I am not aware of signing any waiver. I believe I received a letter saying I was entitled to these payments for life.

Section 8. Other Issues

42. I wrote a letter to Gloucester Royal Hospital asking for my transfusion records. On 30 April 2015, I received a whole stack of documents relating to different aspects of my medical care in the eighties but most of it is illegible either due to the handwriting or the quality of the scanning/copying. Included is a letter from the Gloucestershire Hospitals

NHS Foundation Trust, explaining that the microfiche from which the copies relating to my blood transfusion were made, had not reproduced very well and that this was the best that they could do. The pages concerned are basically black with no discernible print. I was charged £10. I exhibit the letter and the illegible scanned documents as **WITN4135002**.

43. As I mentioned earlier, I had really bad depression after I gave birth to Scott which broke up my marriage. There were days I would be crying and even though I continued working, I struggled to get through my day. It was like I was in a great big dark hole that I was trying to climb out from but I was getting nowhere.

44. I have since officially been diagnosed with depression, around the same time I was diagnosed with Hepatitis C after my father's passing. I am currently on 40mg of Citalopram, which is an antidepressant.

45. I recently moved down to Coleford, Gloucestershire in November 2019 and I have been a lot better since I have been down here, mainly because I now have my family around me.

46. I realise that I was given blood because I needed it and it probably saved my life. I am grateful for that. However, it was contaminated and I believe that I have the right to have expected that the blood I received would be clean.

Statement of Truth

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

Signed

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Dated

9-9-2020