Witness Name: Stephen Andrew Stubbs
Statement No.: WITN0432001
Dated: 10 May 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF STEPHEN ANDREW STUBBS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 January 2019.

I, Stephen Andrew Stubbs, will say as follows: -

Section 1. Introduction

1. My name is Stephen Andrew Stubbs, born GRO-C 1958. I live in Bradford, my full address is known to the Inquiry. I am a father and husband. I work as a porter at the Bradford Royal Infirmary ("BRI"). ✓ yes

2. I intend to speak about the Hepatitis C Virus ("HCV") infection that I received from infected blood products while being treated for severe haemophilia as a child and throughout adult life. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it has had on my life and families lives. ✓ yes

3. I do not have legal representation in regards to the Inquiry. ✓ yes

4. I am aware of the ability to have my statement be anonymous. I have not elected anonymity. I have nothing to hide and believe it is important for the public to know what happen to me. ✓ yes

5. I have recently been diagnosed with early onset dementia. I am awaiting an appointment with the specialist for a full diagnosis and treatment plan. Between the fatigue from my HCV infection and dementia sometimes my ability to recall exact dates and times is effected. Some matters I can recall in great detail, other matters I have gaps in my memory about. Despite this, through deduction of life events I have been able to give approximate time frames for matters. These timeframes should be accepted as 'near to' rather than precise dates. ✓ yes

6. I am aware my wife, Wendy is also providing a statement to the Inquiry. My statement should be read in conjunction with her statement. ✓ yes

Section 2. How Affected

Severe Haemophilia

7. I was born in Gilstead Bradford in 1958. I was the middle son in a family of three boys. My mother, Edna was a carrier of haemophilia. Medical professionals did not diagnose my haemophilia until 1965/66 when I was seven or eight years old. ✓ yes

8. My mother told people she was suspicious I had haemophilia when I was little. She thought I showed signs similar to my older brother who has a mild form of haemophilia. She noticed I was getting little injuries, she would describe them as 'knocks and spills.' While she was concerned it was never formally addressed. ✓ yes

9. In 1963, when I was five years old I was playing at the playground I suffered a significant bleed. Another child and I ran into each other and smashed heads. I suffered a significant cut on the left side of my forehead, it could be described as a gash. I still have a prominent scar today from this injury. ✓ yes

10. The cut to my forehead bled considerably, I was taken to the local hospital. The wound was too wide to stitch. Due to the amount I was bleeding I required a blood transfusion. This was my first experience with blood products. ✓ yes

11. During the transfusion I was given a bag of blood that was the wrong blood group. I remember swelling up and looking like the 'Michelin man.' I was fortunate that the Sister recognised this error and changed the bag of blood to the right type. ✓ yes

12. During my admission to hospital there was no acknowledgement or checks done about my blood's inability to clot. ✓ yes

13. A week or so after I was discharged, I banged my head on a light switch which required another admission to hospital. While I was treated for the injury there was no diagnosis of haemophilia. ✓ yes

14. In about 1965/66, when I was seven or eight years old I had a tooth removed, the bleeding wouldn't stop. I believe this is when I was diagnosed by Dr Goldie at the BRI with Haemophilia Type A. ✓ yes

15. I would describe my haemophilia as severe. My older brother has mild haemophilia and my younger brother does not have haemophilia. ✓ yes

16. Following my diagnosis, if I was ever knocked or injured I would have to travel to hospital for treatment. I was fortunate that my parents fought hard for me to remain in 'normal' school, rather than be placed as the BRI ✓ yes

doctors recommended in a 'special' school where I would have had to have worn a padded jacket and wouldn't risk being knocked. I liked attending 'normal' school and was grateful my parents supported me to remain in mainstream education. ✓ yes

17. I was an active child and teenager, keen on football, running and hockey because of this, I suffered a lot of knocks. This resulted in a large number of bleeds in my knees, ankles and elbows. I required frequent treatments of Factor VIII injections. These were administered on Ward Seven of the specialist unit at St James's University Hospital ("Jimmy's") in Leeds. ✓ yes

18. Treatment continued to be by way of Factor VIII injection at the hospital until the late 1990s. This is when I was taught to self cannulate the Factor VIII. This meant I could administer the 2000-6000 units as required at home. Self cannulating consisted of me placing the tablet in the vial mixing it with saline, insuring it was not cloudy, injecting myself, then recording as per the administration instructions. ✓ yes

19. I was given clear instructions about how to use, as well as when not to use, such as if the seal was broken. I received advice about how to cope should I experience side effects. There was also a procedure for returning unused Factor VIII back to the hospital if it was close to its expiry date. ✓ yes

20. Over time I had less frequent bleeds with bigger gaps between them. This was in part to do with a change of lifestyle. A combination of growing up and not being able to be as active due to my dropping energy levels. As such, I decided to move from home treatment to hospital treatment at Jimmy's again. Having to return the unused Factor VIII meant it was no longer more convenient to self cannulate. ✓ yes

21. I do not know whether it was a blood transfusions or Factor VIII blood products that caused my HCV infection. I do believe it was one of these which gave me HCV. ✓ yes

Hepatitis C Virus

22. In 1982 I was diagnosed with the Hepatitis C Virus ("HCV"). While I do not recall having any symptoms at the time, there was media coverage about the HIV so I may have gotten a letter about needed to be screened due to have had blood products. I can't be sure if I got a letter or not. I know I was due for a regular check up so was screened as part of this by my haemophilia Consultant, Dr Parapia at Jimmy's. ✓ yes

23. Soon after I was screened, Dr Parapia advised me I had Hepatitis C and got infected from the Factor VIII blood products. He told me that blood had been imported from America. It was dirty blood, coming from '*druggies and low lives*,' and it hadn't been screened or heat-treated. ✓ yes

24. I also remember seeing something about '*dirty blood*' on the news. yes ✓

25. When I was diagnosed Dr Parapia explained to me that HCV affects my liver, not to drink alcohol and that as time goes on it could get worse. I recall him saying I could end up with cirrhosis of the liver. ✓ yes

26. I do not recall being told or given information to take away about to protect others from HCV. Somewhere along the line I picked up I must use my own toothbrush, not to leave hazard waste such as cotton wool following a bleed and that you can only contract HCV through sexual activity if you were bleeding.

27. This diagnosis didn't phase me at the time. I thought 'at least I don't have HIV,' which I know some haemophiliacs where diagnosed with. I thought it was the 'lesser of the two evils' I know I wasn't angry about it, but I am now.

✓ yes

Section 3. Other Infections

28. I have been asked to comment on whether I have been given any other infections as a result of blood products. I don't believe I have been. ✓ yes

29. I was tested for vCJD ('Mad Cow Disease') at BRI following a regular six monthly check up. I was called and told I was clear. ✓ yes

30. I do believe there is a connection between my hepatitis and early onset dementia. ✓ yes

Section 4. Consent

31. As far as I am aware I have never been tested or treated without my consent. I believe I have been treated following receipt of adequate information. I do not believe I have been used for the purpose of research.

✓ yes

Section 5. Impact

32. Having Hepatitis C and the treatment has had a significant impact on me. Sometimes I think 'where has Stephen gone?' I have lost my sense of humour. I am fatigued, I have brain fog and headaches are now the norm. I have lost a lot of energy, it is a contrast from the life I previously lived. I used to be active and now I have to take things slower. ✓ yes

33. I believe that as a complication of the Hepatitis and treatment I received I have developed early onset dementia. ✓ yes

34. In 2004/5 I had a liver biopsy that showed I had scarring on my liver. I was told this was 'nothing of note.' I remember the doctor reiterated that I should not drink with my liver in the condition it is in. Following the biopsy I had a liver scan in Newcastle. I remember the person who administered the scan saying the scarring was worse than what the biopsy had indicated. I did not have a follow up with the Doctor after the scan.

✓ yes

35. In 2008 I was invited to consider a course of treatment for my HCV. I was provided information and counselled by the nurses and doctor about the possible side effects of Interferon and Ribavirin. We were advised I might have thyroid problems, personality changes, night sweats, drop in sex drive, generally unwell. It was something my wife and I gave significant consideration to as we had a successful nation wide business. There was a lot to consider and weigh up. After much thought I decided to have the treatment.

✓ yes

36. Treatment was by way of, me injecting Interferon into my tummy fat. I also religiously took the Ribavirin tablet at the same time each day, in the evening with food.

✓ yes

37. I cannot recall how long I was on the treatment programme. I had to stop as the side effects were significant and it wasn't showing signs of working.

✓ yes

38. Once I started treatment I went downhill rapidly, it wasn't gradual. It was as almost overnight. My wife describes it like "Someone else came to visit," I was a different person. I was in a constant bad mood. The kind of mood I get in if Manchester United lose. It was as if they had lost everyday. My bad mood never went away while having the treatment.

✓ yes

39. My bad mood effected my relationships with my wife and family. Evenings were difficult as I was more irritable, having gotten more tired throughout the day. It negatively affected our sex life.

✓ Yes

40. The medication significantly affected my memory, I made banking errors in my business because of it. I couldn't work out where I put money, having forgotten I would then accuse others of taking it.

Yes ✓

41. The Board of Directors noticed a change in me. My family noticed a change in me. They wanted to know what was wrong with me. I had gone from a placid, good-natured person to a rude and irritable stranger.

yes ✓

42. The physical side effects included itchy arms and legs. I was like a monkey constantly needing to scratch them. I was tired and run down. The itchy feeling still remains nine years later.

✓ yes

43. While on this medication I would also sleep undisturbed until about 1 pm. I was that tired.

✓ yes

44. I had a weekly check up at the hospital where they monitored my liver function and blood. I remember asking if what I was experiencing were normal side effects. They reiterated it was part of some people's normal reaction.

✓ yes

45. I cannot remember the exact length of how long I was suppose to have treatment for. I think it may have been 12 weeks. Somewhere between the six and nine week mark, in February 2009 I stopped treatment. It was not having an impact on the virus. I understand that initially my levels had gone down a bit but then levelled out. The decision was made to stop treatment due to it not working. I remember being told if it was going to work they would have expected to see results by then.

✓ yes

46. I still have HCV. GRO-C has had the new treatment and is now cured of HCV. I would like to explore further treatment options. However, I need to await specialist advice about my dementia before I consider further HCV treatment. ✓ Yes

47. I do not believe I had obstacles gaining access to treatment. ✓ Yes

48. I still have ongoing side effects from the Interferon treatment. I continue to have the itching sensation down my arms and legs. I suffer from fatigue. The current state of my health means I am very limited in what I do in life outside of work.

✓ Yes

49. I do not believe I have faced stigma with HCV. My family and I have always been aware it is connected to the blood treatments we received.

✓ Yes

50. There is a colleague at work who teases me, calling me a homophobic rather than a haemophiliac in front of my other colleagues. I figure this is him having a joke, I don't react to it but I just tell him "I'm not, I'm a haemophiliac." I have told my other colleagues about my health issues. ✓ Yes

51. I believe it was the impact of haemophilia rather than Hepatitis that affected my education. I sometimes spent weeks in hospital receiving treatment. I have minimal formal qualifications.

✓ Yes

52. The Hepatitis has impacted the ability to run our own successful business. I also used to work as a Sterilising Technician with the theatre equipment. Due to the fatigue and my declining health I have had to change into my current role as a Porter.

✓ Yes

53. This has financial implications for my wife and I. I worry about the future and my ability to provide for us going forward.

✓ Yes

54. My HCV has had a significant negative impact on finances. I cannot get life insurance and I feel bad about that. I don't have the ability to protect my wife and family in the future. I don't believe it's fair that I cannot have the same safety net others have. I went to the Hospital to receive treatment for my haemophilia and I got infected. I didn't agree to be infected, I am not responsible for causing this, but I now have to live with the consequences of it. This is not fair. ✓ yes

55. I worry that this does impact my wife and family. I don't like to see them suffer and worry about me. I think they worry because I could get really sick overnight. I think they worry about what tomorrow will bring. They worry about my treatment. We don't know what the future holds. ✓ yes

56. While my hepatitis status has not impacted my ability to receive dental treatment. My haemophilia does mean any extractions require a hospital admissions, Factor VIII and ongoing monitoring of my clotting levels. It can be quite a process. ✓ yes

Section 6. Treatment/Care/Support

57. I have not had difficulties or obstacles obtaining treatment. ✓ yes

58. I do not believe I have been offered support or an advocacy to do with my Hepatitis. I have not had counselling. ✓ yes

59. I have discussed with the Inquiry Investigator the existence and contact number of the counselling and psychological support service the British Red Cross is running in collaboration with the Inquiry. I have taken the card and will consider calling them. ✓ yes

Section 7. Financial Assistance

60. I have received financial assistance from the Skipton Fund. This would have been in about 2002/3. I received a £20,000 lump sum payment. I receive £757.50 every three months and £505 winter fuel allowance. ✓ yes

61. I think I heard about the fund from the BRI. I do not believe there were pre conditions to the payment. I do not have documentation from before 2017. ✓ yes.

62. Initially it was straight forward applying for the first lump sum payment. Since my new diagnoses of dementia I have attempted to receive further support and assistance that I need. I am aware my wife is having difficulties with the English Infected Blood Support Service ("EIBSS"). I am not sure of the details. I believe my wife will address these issues in her statement. ✓ yes

63. I don't believe it is fair for payments to be ex gratia and have conditions. I believe those Infected should get payments each year. I believe this should be guaranteed. I believe there should be equality between all infected throughout the United Kingdom. ✓ yes

Section 8. Other Issues

64. I do not think it is fair we don't get more money. It is not fair on my wife, not fair on the rest of my family. It's not fair different parts of the United Kingdom get different amounts of money. There should not be an imbalance. ✓ yes

65. There are people who have died and left behind family members. I could be next. ✓ yes

66. It's not fair the health people who chose to import blood products, didn't screen it and now we have to live with the consequences. I want to know ✓ yes

who made that discussion to import and not screen the blood. Why did all these people get infected. I want to know who is accountable for all this. I believe someone should be accountable for this. yes ✓

67. I believe the government should make a decision and put things right. yes ✓

Statement of Truth

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

Signed GRO-C

Dated 10th MAY 2019