Witness Name: Wendy Stubbs
Statement No.: WITN00873001
Dated: 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF WENDY STUBBS

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

I, Wendy Stubbs, will say as follows: -

Section 1. Introduction

1. My name is Wendy Stubbs, born GRO-C 1960. I live in Bradford, my full address is known to the Inquiry. I am a mother and wife. I work as a Clinic Manager having previously spent 37 years as a Registered Nurse for the National Health Service. I specialised in the fields of paediatrics, oncology and post operative care.

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

3. I do not have legal representation with regards to the Inquiry.

4. The Inquiry Investigator has explained the anonymity process to me. I am aware of the ability to have my statement to become anonymous. I have not elected anonymity. I have nothing to hide and believe it is important for the public to know what happened to Steve and our family. This is in keeping with his wishes.

5. I wish to acknowledge that initially I did not make notes. Naturally as time passes, memories can fade. Despite this, I have been able to give approximate time frames for matters. These timeframes should be accepted as 'near to' rather than precise dates.

6. I am aware my husband also referred to as W0432 is also providing a statement to the Inquiry. My statement should be read in conjunction with his statement, WITN0432001.

Section 2. How Affected

Severe Haemophilia

7. In 2003 Steve and my lives crossed paths when we met through socialising at the same live music venue. Shortly after we met, I went for a drink with Steve at the pub and he told me about his haemophilia and the Hepatitis C Virus ("HCV") infection.

8. Steve was born in Gilstead, Bradford in 1958. I understand his severe haemophilia was not diagnosed by medical professionals until 1965/66 when he was seven or eight years old.

9. His mother told me she was suspicious he had haemophilia when he was little. She thought he showed signs similar to his older brother who has a mild form of haemophilia. She noticed he was getting little injuries. While she had

concerns, it was never formally addressed until he was older. I am aware, his treatment was by way of Factor VIII products and blood transfusions.

10. In the early days of our relationship Steve used to treat himself at home, as required by way self cannulated injection of Factor VIII. As Steve's lifestyle had changed, his need for Factor VIII reduced. He no longer treats himself with Factor VIII at home. When he requires treatment, he attends the Bradford Royal Infirmary.

11. Living with someone with haemophilia you are always mindful of what you are planning, doing and how it might place Steve at risk. You have to be proactive to prevent situations which may harm him. It requires ongoing risk assessment management.

12. Stephen and I do not know whether it was a blood transfusion or Factor VIII blood products that caused Steve's HCV infection. I do believe it was one of these products which gave him HCV.

Hepatitis C Virus

13. Steven was diagnosed with HCV in 1997.

14. Early into our relationship Steve told me about his Haemophilia and Hepatitis C. Naturally, as a nurse with some knowledge of HCV I was concerned about the possibility of the spread of HCV infection to myself. I remember Steve telling me it was his haemophilia Consultant, Dr Parapia at St James University Hospital ("Jimmy's"), Leeds who told him he had HCV at one of his checkups.

15. I know Steve visited Dr Parapia at Jimmy's to discuss HCV before starting a relationship with me. I understand he reassured Steve that I would be ok. I was never offered counselling or advice.

16. Prior to this discussion with Steve about how he became infected with HCV, I had never heard of the Infected Blood Scandal. This is despite being an NHS Nurse who frequently dealt with blood products. I was surprised that it hadn't been publicised.

17. While I was not in Steve's life at the time of diagnosis. His understanding about the illness when I met him was quite rudimental, he was just disappointed he couldn't drink alcohol. I don't believe he had adequate information to understand the impact HCV would have on his life and how matters would deteriorate at the time or in the future.

18. Steve needed better information at the time of his diagnosis. I believe this risk to his overall health should have been explained in detail.

19. Fortunately, I have helped educate our family and we have been able to be protective of the grandchildren around bleeds. I am strict with the laundry because Steve bleeds on the pillows, due to shaving and scratching.

20. I don't believe how the test was communicated to Steve - in a checkup, was the most appropriate thing. I think they could have been more sympathetic, and provided a greater explanation – not just to Steve but also to his family.

Section 3. Other Infections

21. I do not believe Steve has been subject to any other infections.

22. Through the research I have undertaken, I do believe there is a connection between his hepatitis and early onset Dementia. I will discuss this aspect in further detail at paragraphs 48 - 62.

Section 4. Consent

23. I believe Steve would have consented to have his blood tested but would have been unaware it was for HCV and HIV until he was told of the results. I am concerned the testing and consent for the test would have been done in a blasé fashion and without a full explanation.

24. I don't believe he was fully informed prior to the test about HCV and as I have addressed already I don't believe he was adequately informed about HCV following the diagnosis.

25. I believe Steve was tested because "they" - the government, NHS, Hospital, Consultant and The National Blood Transfusion Service wanted to know how many were infected. I believe they looked through the batches and thought - 'Oh, this is another one, we should test him.'

Section 5. Impact

26. The impact of HCV and the treatment can only be described as life changing. In short, I have lost the one I love. Steve is here in body and name, but he is not here.

27. To provide context for that statement, in 2008 Steve and I, along with a business partner, started a company called "Bariatric Surgical Company" which was a surgical weight loss company operating out of Leeds and London. It was a family run company. I was the Clinical Director and Steve the Financial Director. Steve was also my 'Right hand man' when it came to client engagement and care at our clinic which included one fortnightly in Harley Street, London.

28. Steve was very good at his job. He was reliable, accurate, great with clients, patients, and business people. Our Board members liked him, he could articulate himself and had good business acumen.

29. Physically, before the Interferon treatment he was always itchy, generally in his legs but sometimes in his arms and face. There would be times he would be so itchy he would scratch himself to the point of drawing blood. He would describe it as 'Driving him fucking crackers.'

30. He used to have flakey terrible skin, almost like eczema but it wasn't. It was like his skin was always dehydrated despite him not being dehydrated.

31. Steve would also have very bad cramping in his calf muscles, joint pain in his knees, neck and hips. Fatigue and brain fog was something Steve always had to manage. He would get more tired than everyone else. He could fall asleep at the drop of a hat after a big day at work.

32. During 2010 you could describe our life as being a 'Full plate,' Steve had lost his father which hit him hard, I was diagnosed with cancer and we had turned our £10,000 investment into a company with £3 million turn over. Despite all of this, at work he was totally focused and coping.

Treatment

33. Things changed when the Interferon treatment started. In 2011, prior to starting treatment Steve and I had two meetings with Sue, the Haemophilia Nurse at the Bradford Royal infirmary who repeatedly said 'This is something you should be doing.'

34. Sue suggested on a number of occasions that we should get counselling on whether it was right for Steve, she gave us two names and we went to see one.

35. The treatment programme was to be for 12 weeks and involved administering an injection into his stomach and taking a tablet. I was interested in the data about what the success rate was. I was worried he was to be a "guinea pig"

and would be given a placebo. I knew Steve was very keen to eradicate the HCV from his system.

36. We were given an explanation about the side effects, I was hesitant because the list was extensive. The side effects I remember being told about were: thyroid problems – it could even stop working, mood swings, loss of sex drive, forgetfulness, nauseous, vomiting, sleepless night, concentration type symptoms and itching may get worse.

37. We came home and had a chat about it all. We mulled over symptoms. Steven didn't think he would get any of the symptoms. Steve thought he was lucky to have the opportunity to get rid of HCV and was keen to proceed. I said, I would support him if that's what he wants to do.

38. On 30 March 2011, the 12 week treatment of Interferon and Ribvererion began. He was unable to complete the treatment. He got every side effect I list at [36] other than the thyroid problems.

39. The impact of the treatment was almost straight away – we all noticed a complete change in him. He wasn't himself, he wasn't able to function normally he was forgetful, moody, rude, more tired than his normal fatigue, he was irritable especially around kids, didn't like noise, he was off his food, didn't go to sleep, fidgeting and itching, he lost his sex drive.

40. It took a toll on our relationship, I thought he had gone completely off me. He was not a nice person to be around. I couldn't express my love for him, he was irritated by my presence.

41. He didn't want to attend family birthdays or dinners, when I did manage to convince him to come to friends for a curry, he would fall asleep. It was very hard trying to excuse him and his negative behaviour towards people who cared about him.

42. He had an important role in the business which he couldn't do. He upset family and business colleagues. He made banking errors at work, he forgot where he put some money and then accused someone of taking it. Steve refused to take time out from work but those working with him couldn't tolerate his behaviour and errors. It got to the point where the Investor said he would rather pay Steve's salary and for him to stay at home than have him at work. It created tension and was stressful trying to manage,defend, make excuses and protect Steve.

43. I tried explaining it was only going to be temporary. I needed people to cut Steve some slack because of the treatment, but it was also hard when he had become a completely different person.

44. As a result of the treatment our life was completely falling apart and there was no help or support.

45. During treatment Steve had weekly monitoring, I understand they took blood tests, liver function tests, full blood count, alpha-fetoprotein test and thyroid function. In the first two tests there was a positive change which we were pleased with. The following weeks there was no change. Steve was living with all the symptoms but without any improvement. The decision was made to abandon treatment at week six or seven. It wasn't working for Steve.

46. I felt totally abandoned. There was no support, no counselling, nothing to address failed treatment, nothing to address the impact this treatment had on all of us. We were left to pick up the pieces. The professionals just moved us on.

47. Following treatment we were left with a different man. Steve wasn't on the medication anymore but 'pre-treatment Steve' never came back. The damage was done. There were some improvements in his cognition, clarity, initiative,

ability to be left alone, our relationship and his relationship with family. I would say that over the months we got about 70 % of him back. We had to get used to a new normal.

48. In 2012, I was concerned with Steve's cognitive changes and the impact it was having. I was concerned about dementia. The GP was reluctant to refer Steve to a clinic because he was so young. No MRI was discussed. I was 'brushed away' and told to come back if I needed to.

49. Over the years we closed down the business, relocated into a smaller home, and made excuses for Steve's forgetfulness. We continued to live with the side effects of HCV and Interferon treatment.

50. In 2017, there was a noticeable change in Steve, he would forget his garage keys so would break a window to get into the garage, only to later find the key in his pocket. His humour and personality disappeared.

51. Around Christmas time I made an appointment with the GP and took notes I'd made with examples of things which Steve accepted had happened. We were referred to the Memory Assessment Clinic (UK) in Bradford. However, they declined to see him initially because of his age. We had to go to Mr Busby the Neuropsychological Consultant. We had to wait seven months for an appointment, during this time Steve's health continued to deteriorate.

52. In June 2018 Steve had a brain scan prior to the assessment. I remember I had to call repeatedly to get an appointment and was told they were a very busy service. I was at 'my wits end', not having any answers or support. I told them 'One of us will end up in a straight jacket and it's highly likely to be me, because my husband is in happy land.'

53. Finally in November 2018 the cognitive assessments began. This was twelve months after the referral. They were undertaken on the 13th, 29th of November, 13th of December and 14th of January 2019.

54. From these assessments a report was prepared dated 12 February 2019. I understand Steve's cognitive assessment loosely described him as having Dementia with traits of Alzheimer's disease. When I explored this with Kate Wilkinson, the Psychologist, she explained dementia is the overarching diagnosis. The Alzheimer affects Steve's recall, reaching into deep and dark places at times. She explained the dementia is what affects Steve's behaviour and mood related behaviours.

55. On 4 April 2019, Steve and I saw Dr Busby. He listened to me and recommended another four blood tests where required that day. No explanation was given and I didn't ask, but I later found out it was to check for Lupus. It was good to know my research and hunch was on the right track.

56. During the same meeting Dr Busby explained the assessment concluded a diagnosis of dementia. Dr Busby wouldn't discharge Steve, but did also refer him to the Memory Clinic. He said Steve needs dual care. Dr Busby advised that having natural dementia meant things would only get worse. It is a new challenge, a very big challenge.

57. Mentally, it is very hard to know nothing will improve, it is life limiting and psychologically it's difficult not to panic. I know I will be on my own sooner than we planned.

58. Steve currently believes it is 1999 and Manchester United have just won the treble. His behaviour is at times very challenging. He has had to be removed from having access to our bank accounts and the computer, he tried to buy a Scooter off Ebay in Holland. He doesn't have a license to drive a scooter. We have had to advise the Driver and Vehicle Licensing Agency of his diagnosis,

Steve is now only allowed to drive to and from work in his car while his ability to safely drive is further assessed and reviewed.

59. Steve used to do crosswords he now cannot remember anything, names, dates. He is obsessed with cornflakes, only shops at Morrisons, counts spoons and forks. There is no relationship between us. He sees me as a friend. He relies on me for everything. He doesn't function. I have lost my husband.

60. I believe Steve's early onset Dementia with traits of Alzheimers is as a result of his HCV infection. I have spent a significant part of the last two years researching, asking questions of the Doctors, trying to figure out what is happening to Steve. I'm determined to fight for him, to ensure he gets the help and support he needs. I don't want him to be 'pushed to one side' because he has haemophilia or smoked.

61. HCV is a destructive virus. I understand it is often a contributory factor to other illnesses. It is an auto-immune disease which impacts other areas of the body. The aggressive part of the HCV and dementia has taken Steve away from me, I believe they are interconnected. His deterioration has been significant over the last six to twelve months.

62. Steve is happy that the assessment with Dr Busby has been completed, as he can now go for a discussion about possible further HCV treatment. I have reservations about further treatment, but Steve is determined. He has registered his interest and is having an abdominal ultrasound to start the process to see if he is a suitable candidate. If Steve is deemed suitable, I would like a lot of information and meetings with the Doctors to ensure we know what we are getting into.

Impact on myself

63. I believe HCV has had a direct impact on my husband's dementia. I believe HCV has robbed him of his ability to be a husband, to be my partner, my soul mate have any 'normal' life we had planned.

64. I am frustrated by the whole process and system. The establishment has let my husband down. The man I fell in love with and married is no longer here. I am psychologically tired of fighting his corner and feel like no one is listening. The GPs are under time pressure to get you out the door. While Dr Busby and Kate listen, they aren't in my shoes.

65. I feel abandoned. I am lucky to have a neighbour who is great with Steve, and two close friends, my daughter and grandchildren to support me. Despite this, the week he tried to buy the scooter, I wanted to jump in the river. I was not and am not suicidal, I was at my wits end. I am so tired of it all. I am so very tired. That night I felt so helpless I wanted to run away. Two friends and my daughter told me, they were here and would be hanging in there with me.

66. I survived cancer, and I have asked friends, 'Why did I survive cancer to be enduring this torture? I live with someone who is like a baby.'

67. I am fortunate to have family support but I do try to protect them.

Stigma

68. Fortunately all the children know, are educated and are accepting of Steve and his condition. We try to protect ourselves from possible stigma. I believe Steve thinks of himself as being 'Dirty', he has picked this up somewhere.

69. Steve's workplace is aware of his HCV condition, and it did not phase them. His colleagues know a little, but I don't think they really understand.

70. While I don't go to the dentist with Steve, I cannot comment on this. I have only experienced him being treated well when we are in A&E or receiving treatment.

71. Saying that, I really don't like that displayed on the front of all of his medical notes is the word 'BIO-HAZARD'. I don't think they should have that identifying sticker on Steve's documents. There is no privacy with this being on the outside of documents and breaches confidentiality.

Section 6. Treatment/Care/Support

72. I do not believe Steve has been offered support or an advocacy to do with his Hepatitis "C". I have not been offered or received any counselling.

73. I think it is disgusting, there is no support, it's like you are a number. The establishment don't seem to give a hoot. They gave him this infection, he didn't ask for it and yet they send him away. Leaving him to deal with it all. Leaving us to deal with it all.

74. Hepatitis C is a high risk infection and can be life limiting. There should have been counselling and preparation for the patient to be fully informed on the impact it will have and any support that can be offered. We only know what we know about the connection with dementia because of my own research and tenacity.

75. I am happy to speak to others. I am at a stage where I need to talk to someone. When you are a child, if you need support or to know the answer you go to your Mum and Dad, a trusted adult, they have the answers. There is no one. I am tired, so tired. I am exhausted by it all. It is relentless.

76. I have discussed with the Inquiry Investigator the existence and contact number of counselling and psychological support service the British Red Cross

is running in collaboration with the Inquiry. I have taken their card and will consider calling them.

Section 7. Financial Assistance

77. Steve receives financial assistance from the Skipton Fund. He received a £20,000 lump sum payment. He receives £757.50 every three months and £505 winter fuel allowance.

78. I think we found out about these 'piss poor' payments from the hematology department at the BRI.

79. Initially it was straight forward applying for the first lump sum payment and the Stage One payments have flowed from there.

80. What has been difficult and made me angrier and angrier is the process of the Stage Two payments from the English Infected Blood Support Service ("EIBSS"). I have applied for the Special Category Mechanism (SCM) Stage Two, payments because I believe 100% that the early onset dementia and cognitive issues are directly linked to his because of his Hepatitis C Infection.

81. The process is frustrating. Originally I sent the application for Stage Two off in 2017. While I do not have the letter, I recall it was from James at EIBSS and there was a comment about there being no history of diagnosis of fatigue in the GP notes, nor was there a note about his mental health diagnosis. Steve of course doesn't go to the doctor when he is tired. He is often tired and understands, it's par for the course with HCV.

82. Following this response I left it and my distress and anger simmered away for 12 months. In March 2018 I applied again and began to email correspondence with James (EIBSS Representative). He requested the research I discussed about the connection between Hepatitis C and dementia.

83. Prior to me emailing this through, I received notice the application was declined. This made me very angry. I have written an email to confirm that the panel had the research on the Hepatitis/Dementia connection and an explanation as to why it was declined. The EBISS have not replied to my email.

84. This is extremely frustrating, especially when coupled with the decline of Steve's health and the ongoing testing he has required. It is another thing to manage. I am exhausted by it all.

85. In March 2019 I called the EIBSS and said I wasn't satisfied. I complained to them over the phone. They agreed to send a further application. Since this time we have seen Mr Busby. I have resubmitted a new application with the supporting information about the causal link with dementia and fatigue. I believe the GP and Mr Busby support the application. I am hopeful for a positive outcome.

86. Overall this process is not easy. I was alarmed to find out people in the UK are paid differently depending on locations. I think of it as 'Shut up money', there's been a cover up and I feel Steve has been paid to keep quiet. We haven't gone down a formal legal route because Steve decided it would cost too much money. The amount he gets from the fund is not enough - How much is a person's liver worth? And in our case, Steve's brain?

87. I understand there has been a recent increase in the amount Steve will receive from July 2019. I wonder if this is due to the Inquiry.

88. Those involved in the administration of the fund need to know it is difficult for us, you are asking us to put into writing enough information to fit your criteria. It can be hard to accurately explain how things really are, there is no meeting face to face, it is impersonal, there is no dignity in it. Someone at a desk to say yes or no. They aren't living in our shoes.The categories are difficult to

comprehend. I don't know how a lay person would manage, especially on their own.

Life Insurance

89. Steve cannot get life insurance, he has tried to apply. There was one company who would consider him but the premium was extortionate. I had to get the critical health insurance and mortgage insurance in my name. I can no longer get life insurance because I have survived cancer. We are now overwhelmingly disadvantaged.

90. Not being able to get life insurance has been upsetting for Steve. He has been suffering with medical conditions all his life and he can't get financial protection to protect his wife and family. It is critical insurance he cannot get. This is grossly unfair.

91. It's not fair because he was given something he didn't ask for, its affected the financial future and safeguarding for when he dies. It's critical insurance he can't get. It is disgusting the NHS infected him and now he lives with all the consequences.

Section 8. Other Issues

92. As a Nurse I had thorough training. Before you give a patient any drug - oxygen, blood, medication; you must check - name, date of birth, the person in front of you, you must check it all. When you check blood you check the donor and recipient patient, two Nurses must check, they are accountable. As a nurse you sign to say you were accountable for administering the right blood group to the right person. The same accountability and checks don't seem to have applied here, this is double standards.

93. I want to know why this blood was imported. Someone must have known this blood was contaminated. Why the UK couldn't provide their own blood? Was it because of money? Or not enough stock? Why were there no rigorous checks in place?

94. If there were checks then who decided this infected blood could be used on people, innocent people like my husband.

95. I want to ask the question of those making decisions from this Inquiry. If you were in a serious road accident and needed an urgent blood transfusion but the only blood available was contaminated with HCV and HIV would you say yes?

96. We have a duty of candour to our patients and our government has breached our trust and duty to its public.

97. My husband through no fault of his own has haemophilia, he has trusted the NHS all his life and I have worked in the NHS as a nurse all my life. To cover up such a despicable act is beyond words from an intelligent person.

Statement of Truth

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

Signed GRO-C

Dated 11th September 2019.