Witness Name: Mrs Vivien Smith
Statement No.: WITN1977
Exhibits: 0
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INFECTED BLOOD INQUIRY
WITNESS STATEMENT OF MRS VIVIEN CLAIRE SMITH

Section 1: Introduction

1. My name is Vivien Claire Smith, my date of birth GRO-C 1945. My address details are known to the Inquiry. I am the widow of Terence Smith who was infected with hepatitis C by a blood transfusion. We have two daughters who are aged 42 and 45.

2. My husband passed away on the GRO-A 2017. His death certificate states that the cause of death was "*I. (a) End Stage Lewy Body Dementia; II. Multifocal Hepatocellular Carcinoma secondary to transfusion acquired hepatitis C. Conclusion: Died from medical complications to which he was susceptible due to Hepatitis C, which he contracted from an historic infected blood infection*". I make this statement in his memory.

Section 2: How Affected

3. My husband Terence and I were married for almost 50 years. As a person he had plenty of energy; he loved to play a lot of bowls, he enjoyed gardening,

loved walking and loved the countryside. We enjoyed holidays away abroad together. The hepatitis C changed his whole life.

4. On 25 February 1987; my husband, Terence Smith went into Frimley Park Hospital, in Surrey for a gastroenterostomy and partial gastrectomy. An operation that we were told was fairly routine. My husband remained in the hospital following his operation as no food was able to pass through him. On 13 March 1987 he had to undergo revision surgery of his gastroenterostomy. I was given various differing reasons as to what the problem was; to this day, I still have no idea why this happened. Following the first surgery my husband really struggled with his diet; nothing went through him and he started to lose weight. I was told the tube that was inserted was kinked or had sealed across. In any event, his weight plummeted to six and a half stone and they decided to give him a blood transfusion, I think it was because he was so weak after the first operation. It was never explained why it was needed, and I cannot recall whether he was informed that he would be transfused. Many years later when he was found to have hepatitis C we were told that the blood he was given during this operation must have been contaminated. I am aware that within the notes that we have received from Imperial College that there is a note from a doctor stating that Terence had an operation in the late 1970s for stomach ulcers and that during that operation he received blood transfusion; however, I am not aware of this ever taking place.

5. My husband did not suffer from a bleeding disorder.

6. Before my husband was given the blood, I don't think either my husband or I was given any information or advice about any risk of being exposed to infection. With all of the medication that he was given following his surgery, he was hallucinating and so I am not sure he would have understood anyway. If my memory serves me correctly, the transfusion and its risk were never discussed with me either.

7. My husband was infected with hepatitis C only, he had HCV Genotype 3A.

8. On 20 October 1998, around 11 years after being given this blood, my husband was working for Frimley Park Hospital in the transport department. One of his duties was to collect the clinical waste for disposal. He unfortunately sustained a needle-stick injury. He was told that he would have to have a blood test at that time and then again six months later to see if he had caught any infection. The first test; however, showed that he had hepatitis C, although he was not to find out until five months later that this was the case. A positive result from the samples given at this time was much too early for the hepatitis C to have come from the needle-stick injury. In fact his medical records show that tests were completed on samples that were provided to the clinic on 28 January 1999. I have seen a record that was written by Dr Drury who was Frimley Park's Occupational Health Physician who wrote to Terence's GP on 24 March 1999 stating "*Mr Smith had an alleged needlestick injury in October 1998 and has subsequently been discovered to be Hepatitis C positive. Some doubt existed as to whether the Hepatitis C had arisen as the result of the needle stick injury and further testing of the original sample revealed that Mr Smith was Hepatitis C positive prior to his alleged needlestick injury. It is likely that the origin of his Hepatitis C is from a blood transfusion he had some 12 years ago*". Terence's GP medical records state that he tested positive for Hepatitis C antibody test on 13 March 2000; this was one year following the date of Dr Drury's letter to the GP and a year following a letter from Frimley Park (found in the notes from Imperial College London) which records that on 31 March 1999 Terence's "*Hepatitis C RNA was positive by PCR*". It strikes me as odd that Terence's GP medical records indicate that on 25 March 1994; 21 April 1994; 7 July 1994; 15 September 1994 that Frimley Park Hospital conducted liver function NOS tests and that the GP surgery also conducted the same tests on 21 April 1994. There were no results recorded against these particular tests; however there are results recorded against some other tests taken around the same time. For example on 15 September 1994 my husband's serum bilirubin level was recorded as 12 MCMOL/L. On the 22 May 1996, it seems that blood was sent for serum lipids again at Frimley Park Hospital and again there are no results. There are further records in the GP records that show that on all of the dates

above but also on 21 August 1995, 2 January 1996 and 13 May 1996 there is a note against each entry saying "*Refer to pathology department*". I am struck by the regularity of and short intervals between these tests and particularly by the fact that the 1994 tests were recorded to be liver function tests; I am not sure whether Terence would have had his liver function checked as standard while working at Frimley Park whereas he did have his hepatitis B vaccinations on four separate occasions between September 1994 and September 1995 and I think this was standard practise back then. I do not know why these liver function tests were conducted in the first place or why they were conducted at that particular time. They seem to be restricted to this time frame.

9. My husband was told about the hepatitis C infection by the Occupational Health Doctor, Dr GRO-D. I thought that it was in around March 1999, although I note that his GP records state that he tested positive for the antibody hepatitis C test on 13 March 2000. He went to the Occupational Health Office and was told straight that he had tested positive for hepatitis C and that he would have to '*learn to live with it*'. I remember Terence calling me at work after his meeting and telling me. Neither of us knew what it meant. I went to see the nurse who worked at the school where I worked; just to see if she could help to inform me, she did some research on it for me. We found out that there was no cure and that there was a risk of passing it on. My husband was given no information about hepatitis C at that time and especially nothing about the risk of passing it on to anyone. He was also offered no counselling and just like Dr GRO-D had said, he was just left to get on with it. He was, however, referred to Professor Taylor-Robinson, a hepatologist at St Mary's Hospital in London. When he eventually saw the Professor, which was in June 1999, we were given information about the infection.

10. I believe that the information that was eventually given was adequate; it did help us to understand and manage the infection, but only to a degree. The thing that we were most aware of was to avoid blood contact. For example, I brought gloves with me wherever we went. We were led to believe that Terence's Genotype (3A) was one that was '*slow*' developing; it was thought

that it would not advance very quickly. It was thought therefore that Terence would live a normal length of time. As the years went by our knowledge of the infection grew. I remember that the Professor did try to help us in our understanding of the infection and referred to Terence and me to other medics who could help.

11. I think that the diagnosis and the referral were dealt with quite quickly in the end. There was a period of delay between the diagnosis and referral and it might have been helpful if we have been provided with some information to help us understand what we were facing.

12. I think that when he was told he should have been given more information on what the infection involved. It would have been nice to have known what we were facing and to have had more support. I think that they should have had us both in the office and informed us at the same time. I think this situation was dealt with very harshly by Dr GRO-D. I feel very bitter about the way my husband was treated especially because he had been infected by the hospital that employed the doctor who told him, where my husband had also worked as a loyal employee.

13. The risks were communicated to us. We were told not to share toothbrushes or razors or nail scissors and to avoid blood to blood contact. We were told there was a small chance of transferring the infection through intercourse.

Section 3: Other infections

14. I assume that the only infection my husband received from the blood transfusion was hepatitis C. I know that he was tested for HIV and had not contracted that virus but beyond this I do not know for sure.

Section 4: Consent

15. I do not believe that my husband was treated or tested without his consent but I do believe that he was treated without being given adequate or full information about the risk of receiving the blood transfusion when that happened. I do not believe that he was treated or tested for the purposes of research. I myself had a procedure, in September 1986 at Frimley Park Hospital. I was given a blood transfusion during that procedure and was not advised of any risk that might attach to receiving the blood. I have not contracted the hepatitis C virus.

Section 5: Impact

16. My husband suffered immensely from the infection. His deterioration was slow and gradual and in the end he was a shadow of his former self.

17. During his illness my husband suffered from depression (depressive disorder), extreme fatigue, constant flu-like symptoms, migraines, and brain fog.

18. During his last years the brain fog turned to dementia which gradually worsened. His medical records indicate in his diagnoses list that he had "*neurocognitive impairment secondary to hepatitis C*". The official dementia diagnosis came in 2014. Professor Taylor-Robinson did tell us that research was being conducted into the relationship between brain fog and dementia. At that time Terence had lost his driving licence which was the most difficult thing for him to bear.

19. As I mentioned above, my husband developed and died from liver cancer. Terence had liver biopsies in 2001 and 2009 and a fibro-scan in 2011 which was considered to be "*reassuringly normal*" with no evidence of "*significant fibrosis*" so that the hepatologists decided there was "*no good clinical reason to advocate antiviral therapy currently*". A liver biopsy in 2013 showed "*normal liver stiffness*"; he was considered to have mild fibrosis which had not developed since 2001, this was one of the reasons why Terence continued to opt to wait for an interferon-free treatment option. In March 2017, Terence had another fibroscan, it showed that his condition had deteriorated; the fibroscan

reading was 8.3kPa suggesting severe fibrosis. I understand from his records that he was approved for Epclusa at this time; however, it was thought that an MRI liver scan should be performed in order to rule out HCC prior to commencing that anti-viral therapy. Terence was diagnosed with hepatocellular carcinoma soon after, in June or July 2017 and he passed away in October 2017.

20. My husband did try having treatment with pegylated interferon and ribavirin but he had such a bad reaction to the interferon that he was admitted to Frimley Park Hospital, so it was decided that he had to stop the treatment. They said that because he had suffered such a severe reaction after one dose, he should stop and wait for interferon-free type treatments coming onto the market. He was physically very sick and had horrendous migraine. As I mentioned he was approved for Epclusa in June 2017 and at that time had severe fibrosis, it was decided to perform an MRI to rule out hepatocellular carcinoma before commencing this new anti-viral treatment. Unfortunately there was no other treatment for Genotype 3A until 2017 at which time they found he had the liver cancer. Further treatment was not then considered.

21. Terence was unable to get the treatment as soon as it became available because we were told there were others more seriously ill than him. There did not seem any priority for those that had been infected via blood products. I found it very hard to accept that they would not treat my husband with the new Genotype 3A treatment because they felt that there were others more seriously ill than him; he had severe fibrosis and was approved for the anti-viral drug that he had waited so long for, he died in 2017. He was obviously seriously ill at this stage. It upset me to think that there were others who had not been infected in the same way as my husband who were being prioritised above him in the race to treatment.

22. There were no treatments for my husband's Genotype 3A until 2017. I know there were other treatments available for other genotypes. I think that this must have been because certain genotypes were easier to cure.

23. My husband was only given one dose of the Interferon and Ribiviran combination therapy; he could tolerate no more. He had such a violent reaction that he was taken off it and it was not considered again so he waited for the availability of a new drug to treat him, which came in 2017 but which was not then made available to him because of prioritisation and he passed away in October of the same year.

24. I do not believe that my husband's infected status impacted upon his treatment for any other conditions.

25. Obviously when grandchildren came into our lives we were always very careful with them as we did not want to pass on the virus to them. My husband was very often unwell and we had to turn down a lot of social events and the fatigue made it difficult to do some things. When the dementia got worse my husband was unable to carry out work that he used to do around the house and even little things became very difficult. Unfortunately, when my husband was first diagnosed with hepatitis C we were warned that he might pass it on to me through intercourse and advised that he should use a condom. This was something that he found unable to use and so from the age of around 50 that part of our marriage was affected. We were also very careful with the grandchildren in case he passed the infection to them. We were told that it was best not to inform our friends that my husband had the hepatitis C virus because of the stigma attached to it. We, therefore, found ourselves constantly trying to cover up for the way he was feeling and making excuses for not being able to do things. This put a great deal of pressure on both of us as we couldn't get the support from our friends. However, after about ten years we decided to tell them and they couldn't have been more supportive, so in fact what we had been told put us under far more strain than if we had ignored it. We did, however, tell the rest of our close family and although they were obviously very upset they were also very supportive to us.

26. As time went on, my husband became very tired and he suffered from many migraines. There were many times when he would say that he could not attend things with me. Sometimes I would go and other times I would not. I don't think that until he got the dementia that I ever thought he was going to lose his life and even with that I did not think that the hepatitis C would kill him. It was very hard on him and all of our family. The dementia was the hardest part of the whole thing. Seeing someone forgetting how to do everything is very hard to watch. In truth, I am most angry about the way in which Frimley Park treated my husband over his job. I have touched upon this in more detail below. In some ways, I am relieved that his suffering has ended.

27. In relation to the stigma, I don't believe that we did experience this. In hindsight I would have liked to have been honest with people from the beginning and to have had their support. So, the fear of the stigma that the medical profession had instilled in us was greater than what we actually experienced.

28. The infection had an effect on my children. Until he had the dementia we tried very hard to lead as much of a normal life as we could. I think my children got used to Terence being ill. They just accepted it; that he was not as healthy as he could be. I don't think that it had a great impact on them. When he had dementia they took turns in looking after him which was heart-breaking.

29. There were no educational effects but there were significant work–related and subsequent financial effects. Six years after my husband got the diagnosis he was still working for Frimley Park Hospital, he had about one month off work with depression. He was still feeling quite low and Occupational Health asked him to come along to meet with them. Due to the way he had been treated when he was told he had the virus I decided to attend the meeting with him. At that meeting with the same doctor; Dr GRO-D, my husband was told that he should either come back to work full time or submit his resignation. This is a hospital that allowed six months sickness on full pay and six months sickness half pay, as part of their contract. I felt my husband could not be put under any more stress so at the age of 63 he gave in his notice and had to survive on an

extremely small company pension until he was 65. At no time was there any mention of him being retired due to illness. Something I now realise is that I should have fought this but at that time we didn't know enough about the effects of the virus. We were given to thinking that you could live quite normally with the hepatitis C. It was not until we started hearing about other people with hepatitis C that we realised just how badly it could affect everyday life. As my husband never made a lot of fuss when he was feeling so poorly it now makes me realise just how badly he was suffering which in turn now makes me feel quite guilty for not understanding.

Section 6: Treatment/ Care/ Support

30. My husband received excellent treatment and care from Professor Taylor-Robinson at St Mary's Hospital, London. We almost always saw him on our visits so there was good continuity of care. I felt all the tests were done when they should have been and I cannot speak more highly of that hospital and the care my husband received.

31. My husband was never actually offered any counselling but he did at times take anti-depressants. I also had times when I was taking anti-depressants and I did get my GP to arrange some counselling for myself.

Section 7: Financial Assistance

32. My husband and I received financial assistance from the Skipton and EIBSS schemes.

33. In 2004 the Department of Health announced some funding from the Skipton Fund for those that had received contaminated blood.

34. We spoke to Professor Taylor-Robinson about the Skipton Fund; he said to fill the forms in and send them to him for him to complete his part and he would send them off. We duly received the first stage payment of £20,000 two

months following the application. It was this payment that part-funded my husband being able to leave work two years before he received his State Pension. I don't think this is what it should have been used for! We received no more payments until my husband got liver cancer and then we filled the forms in for the second stage payment and duly received the £50,000 from the Skipton Fund in 2017. After my husband died I received £10,000 from the Skipton Fund and then £4,500 towards the funeral. I now receive a monthly top-up of £583, but I understand this will increase to around £868 from June 2019. I call this his '*blood money*'. I also receive an annual fuel allowance of £500.

35. I have to say there were no difficulties when I claimed each of these payments. I didn't at any time try and get any funds or payments from the other Trusts or Funds.

36. There were no difficulties or obstacles encountered in applying for, and obtaining financial assistance.

37. There were no preconditions imposed, as far as I am aware.

38. I have no other comments or observations to make other than to say that the £4,500 funeral allowance was not ever drawn to my attention by the Skipton Fund/ EIBSS even though they were making the £10,000 bereavement payment to me. I accidentally found out about the ability to apply for this sum, on the website.

39. I feel I have answered what I have received above as I saw the payments that were made as being for both my husband and I.

Section 8: Other Issues

40. There are no other issues in relation to which I consider that I have evidence which would be relevant to the Inquiry's investigation.

41. There are no other documents that I wish to identify which I believe may be relevant to the Inquiry's Terms of Reference.

42. I would like to know who is at fault for this and why it was covered up for so long. I would like accountability for this and closure. I am fighting this for my husband, who only passed away 18 months ago want to find answers for him.

43. I find it hard to believe that there are only 30 pages of medical records available on Terence's file at Frimley Park Hospital and that these records do not record specifically the facts that he had a blood transfusion. Terence had two operations at this hospital. I would have expected there to be notes in relation to this within the records. The notes document the following information: "x match 20 (Hb 9.3)" on 15 March 1987 and "2 litres x 12 hours" on 26 February 1987. I assume that these entries referred to blood and provision of it but I am sure there is enough detail to conclude that this is the case.

44. My husband was treated very well by all other medical professionals, other than Dr GRO-D at Frimley Park.

Statement of Truth

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

Signed: GRO-C

Full Name: VIVIEN CLAIRE SMITH

Date: 15/7/19.