

Witness Name: Stephen Smith  
Statement No.: WITN0138001  
Exhibits: None  
Dated: 08/05/2019

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF STEPHEN SAMUEL SMITH**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 April 2019.

I, Stephen Smith, will say as follows: -

#### **Section 1. Introduction**

1. My name is Stephen Samuel Smith. My date of birth is GRO-C1952 and my address is known to the Inquiry. I am a widower. I used to be a private driver before I opened a paper shop, but about twenty years ago I had to give up work because of my illness. I have three children and live with my son who cares for me.
2. I intend to speak about my infection with the Hepatitis C virus ("HCV"), which I contracted as a result of being given infected blood products to treat my mild haemophilia.
3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it had on my life and the rest of my family.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. My eldest

son and my daughter also assist as sometimes I forget names and dates.

5. I am happy for the Inquiry Team to assist me with my statement. My children, Rebecca and Matthew, also assist me, as I suffer from brain fog and sometimes my memory is not very good.

## **Section 2. How Infected**

6. I discovered I was a mild haemophiliac in my teens (i.e. in the early 1970's). I attended the Haemophiliac Centre at the Queen Elizabeth Hospital in Birmingham on many occasions because of bleeds in my joints, bad cuts, etc. To stop the bleedings, I would be given plasma at first, and then when it became available Factor VIII concentrate. I also had a lot of dental work and extractions over the years, which required treatment with Factor VIII.
7. I do not remember being explained at any point what Factor VIII actually was, and nobody ever warned me of any risk of being infected. At the time I did not know that the blood products had been imported from America. I was also never offered artificial Factor VIII.
8. GRO-C who was a haemophiliac too and also contracted Hepatitis, told me about artificial Factor VIII, but this was never mentioned by my own doctors.
9. With insight, I think Factor VIII blood product was given freely by medical staff, without questioning whether a bleed could be managed in any other way. If I had a small cut, they would immediately give me Factor VIII, without even thinking of simply stitching the cut first. I believe they really used too much of it.

10. One day, probably around 1983/1984, I attended the Haemophilia Centre at the Queen Elizabeth Hospital, and the consultant, Dr [GRO-D] simply told me out of the blue that I had Hepatitis C.

11. I did not receive any further information at this stage. The doctor asked me whether I was a drug user and I said no. However, he never mentioned I could have been infected as a result of being given infected Factor VIII.

12. To the best of my knowledge, my wife and children (even my daughter, who was born after my diagnosis) were never tested for Hepatitis, as this was never suggested to me.

13. With hindsight, I wish I had received more information about Hepatitis and its treatment.

### **Section 3. Other Infections**

14. About twenty years ago, I received a letter by post informing me that I had received Factor VIII made from a batch contaminated with vCJD.

15. However, I was not offered to undertake any further test and as such, nothing happened of it and things just carried on. To this day, I have not been tested for vCJD.

16. Beyond this letter, to the best of my knowledge, I do not believe that as a result of being given infected blood products I have contracted any infection other than HCV.

### **Section 4. Consent**

17. I have been asked whether I believe I have been tested or treated without my knowledge or consent. I always consented to receiving Factor VIII, although I was not aware of the risks.

18. I was never asked whether I wanted to be tested for Hepatitis C and I did not know I had been tested for it until I received my diagnosis.

19. To this day, I do not know whether I have ever been tested for HIV. I assume I have been and was simply not told about the result, as it was probably negative.

### **Section 5. Impact**

20. When the doctor told me that I had Hepatitis C, I was gobsmacked, as this happened at the time when Hepatitis and HIV were coming along in the news. After this, my life completely changed.

21. One month later during an appointment, I was told that a treatment was available. My doctor explained to me that it was a trial and he could not guarantee it would work or that I would be able to stand it. He informed me of the potential side effects and the percentage of success. I was given the choice whether to try this treatment or not. I consented to it, because when your doctor tells you there is a treatment and you have Hepatitis C, you simply take it.

22. So, I started the trial which was based on Interferon and Ribavirin. I followed the whole course of treatment for 12 months. I mainly injected myself at home on different parts of my body.

23. I had many side effects as a result of the treatment, including mood swings, depression, loss of weight and loss of appetite. I became very aggressive, and I simply was not the same person I used to be.

24. At the end of the treatment, I was not told whether I was cured or not. In fact, I never seemed to be able to get a straight answer from medical staff as to whether I got rid of HCV.

25. Around 2000, I started to have pain in my ankle. I thought it might be a bleed and so I attended the Shrewsbury Hospital. After a round of blood tests, the doctor told me not to worry, but to come back the following day as they could not find any white cells in my blood. When I came back, I was diagnosed with non-Hodgkin Lymphoma and the consultant told me it was possibly linked to Hepatitis C. At that stage, I asked the doctor whether my infection could be the result of being given Factor VIII, to which he replied: "It is possible".
26. From that moment on and for the following ten years, I underwent very invasive treatment to treat the Lymphoma. At first, I was put on a chemotherapy treatment for two years at the Shrewsbury Hospital. I was told that the treatment was palliative and not curative and the doctors told me that I had a life expectancy of ten years. After this, I had many other rounds of chemotherapy for different grades of Lymphoma. At times, I could be off the treatment for barely six months before I started another round. Then I also had a stem cell treatment at the Queen Elizabeth Hospital in Birmingham, but it was unsuccessful.
27. I believe my cancer is now under control. I am aware that it will never be gone, but my Lymphoma levels are now manageable, and I have not been on any chemotherapy for about two years. However, I have suffered from heart failure and kidneys problems, which means that I have been in and out of hospital for the last two to three years anyway.
28. I have always been treated very well at the Shrewsbury Hospital. However, I did notice that unless I prompted the medical staff and told them that I am a haemophiliac, they did and still do not always remember to take the necessary precautions.
29. My HCV never really impacted the other medical treatments I received over the years. At first, the dentist and nurses would take more precautions, such as putting on another layer of gloves, but I understood, that they did not know much about HCV at the time.

However, I never felt uncomfortable or badly treated when receiving medical treatments.

30. My illness, the treatment and side effects I experienced put a great strain on my relationship with my family. I had a lot of mood swings, and I was not very nice to them.
31. In particular, HCV had a massive impact on my relationship with my wife. My illness really brought us apart. To this day, I do not know how we stayed together, because I was so horrible to her. She shunned me away, and we were never as close as we used to be. We did not have any sort of intimacy anymore. She also kept the children away from me, as she was worried they could become infected.
32. She used to be a post office assistant. After reducing her hours to twelve hours a week in order to care for me, she eventually had to give up her work to assist me.
33. Eleven years ago, she was diagnosed with bowel cancer and she died of septicaemia. Before she died, she told me: "I'm sorry I have been so awful to you all these years"; this always stuck in my mind.
34. Since she died, my children have been caring for me, and I now live with my eldest son.
35. I never told my parents that I had Hepatitis C. I would never talk about it with anyone as it was a real taboo, even at work. I worked at a food shop for a few years, so I could have lost my job, had I disclosed my condition.
36. I have been asked whether my social life changed after my diagnosis. My family and I were very private and we did not really want to socialise that much.

37. After being diagnosed with non-Hodgkin Lymphoma I had to stop working; it is now almost twenty years that I retired. I believe that if I had not got infected, today I would still be working.

#### **Section 6. Treatment/Care/Support**

38. After I have been diagnosed with HCV, I have never been offered any counselling or psychological support, although I think it would have helped me to cope with all I have been through. However, I later received some psychological support from Macmillan Cancer Support in relation to my non-Hodgkin Lymphoma.

#### **Section 7. Financial Assistance**

39. About fifteen years ago, Dr Powell at the Shrewsbury Hospital told me I could seek help from the Skipton Fund. I called them and obtained a form to apply for financial assistance. Dr Powell filled it in for me. I do not remember the exact date but my application was immediately accepted and I received a first lump sum payment of £20,000.

40. After I was diagnosed with the non-Hodgkin Lymphoma, I also received a second lump sum payment, although I cannot remember the details of it.

41. I now receive monthly payments of £1,500.

42. I believe it would have been useful to receive more money. My children had to help me to pay for my treatment with their own money and this is not fair.

#### **Section 8. Other Issues**

43. I have not been involved with any campaigning or any group litigation.

44. I have been asked if I have any expectation from this inquiry. I would like to know what really happened, whether it was just a "blood scandal", and whether people have died in vain.
45. I think someone must have known what was going on. I just cannot believe they used the blood whilst knowing it was infected with diseases. Why was it not destroyed? And why did the UK import infected blood from the US whilst they could have produced their own? In this country we have the best national health service in the world, yet they let something like this happen. I believe this was down to mismanagement.
46. Throughout my life, I have found that the medical world was like a "close shop", and that there was no openness from the medical staff.
47. I also told my doctor at the Shrewsbury Hospital, Dr [GRO-D], that I was going to give my statement to the Inquiry. He was very dismissive of the whole process and told me that it was not worth it.
48. I actually never saw him again, and the Hospital staff simply keep telling me he is away and that they do not know when he will be back. However, he has now been away from quite some time and it is a bit weird; this is regrettable as I had a lot of confidence in him. I would really like to know what happened to him.

**Statement of Truth**

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

Signed

GRO-C

Dated

8/5/2019