

Witness Name: Peter Michael Smith

Statement No.: WITN3309001

Exhibits: Nil

Dated: 29/10/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PETER MICHAEL SMITH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 September 2019.

I, Peter Michael Smith, will say as follows: -

Section 1. Introduction

1. My name is Peter Michael Smith. My date of birth is GRO-C 1957 and I live at an address that is known to the Inquiry, where I live with my wife Anne. We spent the last four years caring for my mother at her house in Hertfordshire. She suffered from vascular dementia. She has passed away. I have not worked since moving back here full time in July. You could say I am now retired. I would like to work part time but have found nothing is suitable yet. From 1975 until 2003 I worked in the money markets in the City of London. After moving to Wales following my illness I have had various jobs but I have mainly worked as a bus driver.

2. I intend to speak about my infection with hepatitis C virus ('HCV') from an infected blood transfusion. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, Anne and our lives together.

Section 2. How Infected

3. I grew up in GRO-C Hertfordshire. On 22nd May 1976 at 10.40pm, aged 18, I was involved in a traffic accident while riding a motorcycle near the Royal Veterinary College Brookmans Park. The driver of the car did not stop after the crash. I was subsequently rushed to Barnet General Hospital.
4. When I woke up from the crash, I was in hospital and my left leg was severely damaged. After being operated on, I was put in an orthopaedic ward to recover. Unfortunately I developed gangrene and septicaemia, the doctors tried to save my leg but they had to amputate it. After this I was lying in bed when my stump haemorrhaged, and the bed started to fill with dark blood, lots of it spurting out. I was rushed to the operating theatre to stop this and given a large quantity of blood as a transfusion. I was given so much they could not give me any more even though it was my group. My Blood count was very low.
5. I was subsequently told that I had been very close to death. For a lot of the time I had been unconscious, and by the time I was fully awake it was all a blur and felt like a surreal experience.
6. After about a year in recovery and with a prosthetic limb, I strived to carry on with my life as normally as possible. I continued my job in the City of London. Every day I would commute into London on the early train, and arrive in the City. My job was in the money markets, and would involve preparing the days information and dealing positions

ready for the traders to come in and then servicing their needs thereafter.

7. One of my interests at that time was football. I used to travel the country watching a variety of fixtures. On the night of 5th November 1983, I went to a Bonfire Night party at DeMontfort University in Leicester (then a Polytechnic) This was when I first met my wife Anne. I approached her and we began chatting. GRO-C
GRO-C We have been together ever since.
8. Anne and I married in 1995. One day in 1996, I was walking to the station in the early morning on the way to work. I had been aware for some time that I was not in the peak of health. I was weary. I became dizzy and my legs weakened. I was forced to sit on the pavement. Eventually I was able to get home, and I went to see the doctors.
9. My GP, Dr Davies at Potterell's Medical Centre, said that he could not find anything wrong with me. I knew this could not be right, and I insisted that he check me more extensively and I had blood tests.
10. Around a week after this, I received a call from the medical centre asking me to come in. I went to see Dr Davies, who told me that I had Hepatitis C. He asked me where I may have got this virus from. I replied that I had absolutely no idea. The only thing that had ever happened to me was the amputation following the motorcycle accident.
11. When I told the GP of the motorcycle accident, I told him that I had a blood transfusion during the surgery. He did not tell me that this could be the cause of my infection. Although I had heard of Hepatitis A and B, I knew nothing about Hepatitis C. My blood tests showed that my liver enzymes were 'through the roof'. They were over 200 when a normal level is 40. Dr Davies did not explain how I may have contracted HCV. Other than telling me not to drink alcohol, I was not

given any other advice about how to help myself and prevent the virus from developing.

12. I had private medical cover with my then-employer, through which I was referred to the Queen Elizabeth II Hospital, Welwyn Garden City. There, I had a liver biopsy. I had argued against having this done; the doctors however needed to know what state my liver was in because of the high enzyme count.
13. The liver biopsy was extremely painful. I was effectively stabbed in the liver while I was conscious. They took a sample. At the Queen Elizabeth II Hospital there was no liver specialist at that time, and certainly no hepatology department. The Doctor there said that I had Chronic Active Viral Hepatitis C, and that my liver was damaged. My liver was scarred, although there was no cirrhosis. An ultrasound test also showed that my liver was hardening.
14. The Doctor said that I had three options; I could either do nothing, and run the risk of developing liver cancer, continue at the Queen Elizabeth II Hospital, where they had no appropriate treatment programme, or the third option was for them to refer me to the Royal Free Hospital, which had a large hepatology department for this type of care. It was an easy decision to make and I was referred to The Royal Free. Aside from this, I was given very little information about HCV. However, I was persistent in my quizzing of the doctor, and I believe they told me all that they knew at that time, which quite frankly was not much.
15. Having requested to be referred to the Royal Free Hospital for treatment, I heard nothing for a while. I went back to the GP to request that he chase this up. I ended up phoning the hepatology department myself and I spoke to the secretary of Professor Geoffrey Dusheiko (Head of Hepatology at the Royal Free). The secretary told me to come to the hospital and find her office, and she would then try and get me an appointment to see the Professor.

16. I did this and I saw Professor Dusheiko. I found him to be frank, straightforward and honest. He said that they did not have a cure for HCV, but they did have a treatment. This Interferon treatment, he said, may work and stop the virus from developing and damaging my liver further. He advised that some people get on with it better than others. I was told that there were potentially some quite bad side effects however.
17. I elected to try the Interferon treatment. The Professor told me that in his opinion given the progression of my liver disease the blood transfusion was the cause of my HCV infection. The blood was not stored properly then, there was no screening or testing of blood. It was only after seeing Professor Dusheiko that I began to do some research and came across the infected blood issue.
18. I began my first course of Interferon at the end of 1996/beginning of 1997. This was due to last for 6 months. I decided that it was not worth risking developing liver cancer by delaying treatment. The treatment involved self-injecting interferon 3 times a week. Right from the start I suffered from severe flu-like symptoms. I woke up in the middle of the night drenched with sweat, with a high temperature and shivers. I was extremely fatigued, and because of this my ability to get in to work was severely inhibited.
19. During the treatment I went for tests every month. The results showed signs that the treatment was working. My liver enzyme count had come down considerably. I had lost a lot of weight, as my appetite was reduced. After 6 months it was decided not to continue with the interferon treatment, though I was better than I was before. It was decided that they would continue to monitor me and see if I maintained improvement after the treatment was stopped.

20. I returned to work after the first course of treatment. The Interferon had taken a lot out of me, and I felt tired and unable to concentrate. Despite this, I tried hard to get properly back to work. My employers knew that I had Hepatitis C and was undergoing treatment. I told my friends at work. They knew very little about Hepatitis C and what the treatment entailed. Although my employers knew of my treatment, I felt that they tolerated me rather than supported me through this.
21. Monitoring tests at the Royal Free Hospital showed that my enzyme levels had shot back up again. The specialist advised me that my genotype of Hepatitis C was difficult to get rid of. They wanted me to go back on the Interferon treatment in order to maintain the enzyme levels and to stop them from increasing.
22. The second course of Interferon treatment was the same as the first. I was self-injecting interferon 3 times a week subcutaneously into the flesh of my stomach. My enzyme levels were monitored regularly to ensure they were not increasing. I was concerned about whether I would develop liver cancer. The specialists were unsure. Despite my persistent questioning about my condition and treatment, the answers were generally uncertain, I do not think they knew.
23. From the end of 1996 through to 2002 I was on and off Interferon regularly. I was monitored regularly, and whenever my enzyme levels showed signs of increasing, I was put back on the interferon.
24. In 2002 I was informed of a new trial by Schering Plough which involved a new type of Interferon combined with Ribavirin. At that time, I had lost a lot of weight and looked unwell. It was explained to me that this new trial was of Pegylated Interferon (Alpha 2b) which was injected, combined with Ribavirin, in tablet form. I was advised that the Pegylated Interferon stays in the blood stream for longer, whereas normal Interferon dissipates in your blood and cannot target the virus as effectively. The Pegylated Interferon would not give the virus a rest

in the same way as the regular Interferon that I had been injecting. I said that I wished to take part in the trial so long as I was given the real drug and not a placebo.

25. I started this combination treatment in January 2002. I did experience some flu-like symptoms, but these were not as severe as before. I have now only recently been informed of the 'Ribavirin rage'; I think this may explain an argument I had with a fellow spectator at the Oval whilst on this treatment. I had a row with someone who kicked the back of my chair. This was completely out of character, and I believe may have been caused by the side-effects of Ribavirin.

26. I stayed on the Pegylated Interferon and Ribavirin treatment from January 2002 to January 2003. After 6 months, I had blood tests and an ultrasound which showed they could not find the virus, though antibodies were detected. After a year, these tests were repeated, and the results showed no signs of the virus or antibodies. I was told that the HCV was 'undetected' and thus 'clear', or as clear as they could be sure though I understand that determination cannot be 100%.

27. In January 2003, having been told I was 'clear', I had lost my job due to non-attendance as a result of my long-term illness. I have not dwelt on this for some time, and have only begun to consider the unfairness of this now, since then start of the Inquiry.

28. Having cleared the virus, I was now unemployed. I was told that my immune system was very weak after all the treatment. As a result, I developed a cellulitis infection in my right leg, which required intravenous antibiotics during a stay in hospital to repel the infection. At one stage they were worried I would lose this leg as well. This infection has caused permanent damage to the lymphatic system in my lower leg. I wear a compression stocking all day while awake to aid circulation and reduce swelling. My walking has been even more difficult since this time.

29. I had to reinvent myself having been cleared of the HCV. My wife and I moved to North Wales, where my grandmother was born, as we could not afford to live in SE England any more with a large mortgage as my wife was the sole bread winner at the time.

Section 3. Other Infections

30. I do not believe that I have contracted any other infections as a result of my infected blood transfusion.

Section 4. Consent

31. I do not believe that I have received any treatment without my consent. I have always consented to be treated with Interferon and Pegylated Interferon and Ribavirin combination treatment. I consented to being tested by my GP when I underwent blood tests in 1996, as I was the one pushing for these tests to be undertaken.

32. The Pegylated Interferon and Ribavirin combination therapy with which I was treated from January 2002 to January 2003 was described to me as a trial. I did consent to being treated with this trial medication.

33. I believe that I was given as much information as doctors were able to give. I was particularly proactive in my questioning of them regarding my infection and the treatment I was given. It was clear to me that the medics knew relatively little about HCV and how to treat it when I was diagnosed.

Section 5. Impact

34. My wife has been of tremendous support to me throughout this ordeal. It has been difficult for us, but her support has made me realise how lucky I am to be with her. During the interferon treatment I had

effectively no libido [GRO-C] [GRO-C]
[GRO-C] Thankfully, we have been
able to deal with this struggle together.

35. Before my diagnosis with HCV, we were not certain whether we should have children. [GRO-C]
[GRO-C] When I was diagnosed HCV positive, it compounded our problems and we decided not to have a family. Although we were uncertain about having children before this, I do believe that my infection with HCV effectively made this decision for us. With Anne as the sole earner for most of this time it was economically impossible as well.
36. I have lost a large amount of income as a result of my infection with HCV. I was unable to work due to the extreme fatigue I suffered from the Interferon treatment. This made my employers lose faith in my reliability, which ultimately was the reason I lost my job in the City of London. We were unable to afford to continue living in South East England. As a result, I was forced to take any work I could until I ended up working mainly as a bus driver when we moved to North Wales.
37. Although I have the occasional drink now, I abstained from alcohol during my treatment with Interferon. This was necessary for the treatment to work. This had a detrimental impact on my social life, which usually involved a social drink at the golf or cricket club, but I was usually too tired to go out anyway.
38. I often worry when I feel any unusual pain or discomfort in my body. I had a blood test a couple of years ago which showed the existence of HCV antibodies in my blood. I worry that this may be my HCV flaring up again. At my age, I believe that I would not be able to go through the treatment again and fight the virus with the same strength and determination as before.

39. I do not believe that I have experienced any sort of stigma around my infection with HCV. If I have been the subject of negative attitudes, I have not noticed it. My employers were aware of my infection, and tolerated my absence during treatment to a certain extent. This tolerance eventually wore out when I lost my job in January 2003.

Section 6. Treatment/Care/Support

40. I did not have any difficulty in obtaining treatment for my HCV infection. I pushed for treatment, and when I was referred to the Royal Free I made sure that I was seen by Professor Dusheiko. It took a while to see him but I made sure it happened.

41. I was impressed by Professor Dusheiko's frankness and knowledge. He was straightforward and I believe he was honest with me throughout my treatment.

42. I have not been offered any form of counselling or psychological support as a consequence of my infection with HCV. I do not know if it was or is available.

Section 7. Financial Assistance

43. I applied to the Skipton Fund in 2002. Professor Dusheiko was on the board of the charity at that time, and he advised me to apply. My application was accepted reasonably quickly, and I received an ex gratia stage 1 payment of £20,000 that year. I did not receive any further assistance of any kind for the next fifteen years.

44. In 2017 I started to receive payments of £1000 every 3 months, when all the different charities and funds merged, and the EIBSS was set up by the NHS Business Authority. This was totally insufficient and unsatisfactory in respect of what I have had to deal with. This

increased to £4,600 every 3 months in July this year (2019). I believe this was in consequence of pressure from the Infected Blood Inquiry and Sir Brian Langstaff. Had these ex gratia payments not increased to this level, I would struggle financially. I also receive a winter fuel allowance of £500 every year.

45. I applied for a hardship payment last year, but was refused as I could not prove that I was 'suffering'. I was incredibly frustrated by this. Occasionally I am unable to walk even 100 yards, the Interferon treatment damaged my immune system causing the cellulitis infection and lymphatic system damage. I was unable to prove that I was depressed, and this was explained as the reason for my rejection. The recent increases from EIBSS have now taken me to the level of the hardship payment.

46. Aside from these EIBSS payments, I now receive no other income. My wife runs a small glass arts and crafts business which brings in some money for her. I do not receive benefits. I will receive a small pension in 2022, which clearly would have been a lot bigger had I not been infected with HCV. My friends still work in their jobs in the City, some have retired and the rest will be close to it now. I believe that I could have continued to work, progress in my career and build up a decent pension were it not for my infection.

Section 8. Other Issues

47. The impact of my infection with HCV has been life changing. I semi-retired around 20 years too early, and was forced to move away from South East England due to financial pressures.

48. Professor Dusheiko said I was very lucky to be cleared of the virus because of its genotype, with only 30% of similar sufferers being cleared from the HCV. I do not feel lucky, I injected myself 3 times a

week whilst I suffered from the severe side-effects of the treatment. I self-administered the medication absolutely to the letter, on time and according to my instructions. I gave myself the best chance of beating the virus while on the trial. I believe some people failed to clear the virus because they did not stick to the regime.

49. I believe that this scandal was borne out of ignorance and laziness on behalf of medical professionals. It was known there was a problem which needed addressing. I am annoyed that I was given infected blood when they knew there was a chance of infection, although had I not been given blood it is possible I would have died following my motorcycle accident.

50. I would like the Inquiry to establish the truth as to what actually happened, why we were infected when the authorities knew that there was a problem with the blood supplies. I would like to be adequately compensated for the damage done to my health, life and finances.

Statement of Truth

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

Signed GRO-C

Dated 29 / 10 / 2019