Witness Name: Paul Walker Statement No.: WITN0275001

Exhibits: nil

Dated: 13-02-2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAUL WALKER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 November 2018.

I, Paul Walker, will say as follows: -

Section 1. Introduction

 My name is Paul Walker. My date of birth and address are known to the Inquiry. I am a retired nurse and was a deputy ward manger. I intend to speak about my infection with Hepatitis C. For which I have successfully been treated.

Section 2. How Infected

 As a child I was diagnosed with Von Willebrand's disease type 2B, after bleeding from being circumcised. There was not a lot of knowledge at the time, and there was no family history of the disorder.

- I had lots of hospitalisations due to bleeds up until the age of 15/16.
 These required blood, but in those days transfusions were given rather than concentrate.
- My mother tells me that I was the first person in Scotland to have Cryoprecipitate.
- In my adult years the bleeding calmed down, except for bleeding gums and nose bleeds. I would have to have blood products for dental extractions. During this time I lived in London and was under St Thomas' Hospital.
- 6. I was pretty well until two bad bleeds in the 1980s that were close together. The first was a nose bleed around 1982/3. I was admitted to Pembury Hospital, taken into theatre and my nose was packed. I recall waking up in the intensive treatment unit and the blood was going down my throat. The packing was therefore removed. I received a transfusion for this bleed.
- 7. Not long after the first bleed, I remember waking up with back pain and started passing blood. I was bleeding into one of my kidneys, where the blood was forming into clots (like a kidney stone). I was again taken to Pembury Hospital by ambulance, where I received whole blood and Factor 8.
- 8. Around 1997/8 my knee locked at work, so was admitted to A and E at Bury St Edmunds Hospital. A paternalistic old school style consultant operated me on, so he decided to test for HCV without asking for my consent. The test came back positive, which was a complete shock and blow at the time.
- I was notified whilst the consultant was on a ward round, and he sat down at the side of my bed. I cannot recall his exact words, but that he had tested for HCV and the results were positive. He

recommended that I should be tested for HIV. I do not remember the implications of my HCV infection being discussed at this point, but happened later on.

- I gave permission for all of the blood products and transfusions I received, but I was never told there was a potential for infection.
- 11. I was rather well until the two bad bleeds in the 1980s, so the infection would have been from the blood products and transfusions given. Apart from a bleed into a knee in 2008, I have had no big bleeds since but do bruise easily.
- 12. The consultant referred me to Addenbrooks because they had a specialist. Graham Alexander regularly saw me, he was fantastic and explained everything in greater depth.
- 13. A HIV test was taken at Addenbrooks but the results took weeks to receive. During this time I attended the counselling session provided as part of the process. Thankfully I did not test positive to HIV.
- 14. A liver biopsy was also taken, which itself had a high bleeding risk. I therefore received more Factor 8 Concentrate. I was monitored for a few years and another biopsy was carried out, presumably because of the liver function tests.
- 15. Hepatitis B is always tested for when you start nursing. I did not have the vaccination as a child because of the Von Willebrand's disease and the risk of bleeding, so I was inoculated.

Section 3. Other Infections

16. I have not received any infection other than HCV as a result of being given infected blood products.

Section 4. Consent

- I did not give consent; the transfusions and blood products were just given.
- I do not recall being asked for consent when I was tested for HCV.
- 19. Consent was not as big as it is now and for a blood transfusion consent was assumed. Whilst training as a nurse, I was told if you ask to do a patient's blood pressure and they consent even by lifting their arm.
- 20. As far as I am aware I have not been tested for the purpose of research.

Section 5. Impact

- 21. Having worked on a hepatology ward as a newly qualified nurse, it was devastating to be told I had HCV. I knew that it could lead to liver disease and failure and what an awful affliction it is. I was aware that it was a slow and debilitating way to die. It knocked me for 6. This may explain why I overreacted a little bit to my diagnosis.
- 22. The diagnosis came as a shock and was a huge blow at the time. In those days not much was known about HCV, but it was very much associated with drug abuse and promiscuous sex. The latter came into the mix for myself, as I am gay.
- I was depressed initially, but this did not last very long. I also lost my temper easily because I was very worried and angry about the infection. I would talk to my partner to voice my concerns and worries, but I just had to get on with it.

- 24. I did not have an awful lot of physical problems, but was wary of situations that could lead to lead to bleeding.
- 25. Not long after qualifying, I was put on secondment as a diabetes specialist nurse. As part of a project, I was put on the path of a newly diagnosed type 1 diabetic patient and the healthcare process they would follow. During an examination for this project, the registrar gave me a funny look. He later took me to one side to say I had spider naevi on my back, lesions caused by liver disease.
- 26. I started straight away on the dual therapy treatment, injecting the interferon twice a week and taking ribavirin tablets. This was around 2001/2. Although I was a nurse, self-injecting the treatment was not nice.
- Initially I was told the treatment was unlikely to work because of the genotype. I do not know which genotype of HCV I was.
- 28. As a couple we had always intended to live abroad for a period. From what I had been told about the treatment, I was under the impression that it would not be a success. I therefore dragged my partner out to our holiday home in Spain, to enjoy a few years abroad, before liver damage would kick in. He did not really want to at the time.
- 29. Fortunately Graham Alexander had a contact in Spain, so all my care was transferred to Manuel De La Marta seamlessly. He was a very efficient doctor. Addenbrooks also provided a supply of the medication, and afterwards I had to negotiate with the Spanish Health Service.
- I had no side-affects in relation to the treatment, except from one incident

- 31. Whilst I was in Spain I was switched to a new formulation of the treatment, which meant I only had to inject once a week. I had a horrendous allergic reaction to it; I developed a rash, felt nauseous, and had a fever. I remember lying on the sofa feeling absolutely miserable, so ended up ringing an on call doctor. He instructed me to change back to the original treatment. I only took 1 dose of the new formulation.
- A post course test was carried out after I finished the treatment in 2003. Much to the amazement of the consultant and I, the virus had cleared.
- 33. On reflection, if the consultant had not tested me for HCV I would not have known until much later on. I am thankful that it was discovered early on and before liver damage occurred.
- 34. In regard to follow up care, I was seen every 6 months and now yearly. I count myself lucky that I am still clear.
- 35. I now worry about my health at lot more than I used to, and am now fanatical about the gym. I do drink but I am very conscious, so monitor what I drink closely.
- 36. I did not face any stigma because I did not tell anyone apart from my Mum and a couple of close friend. When we moved to Spain I did not tell anyone there.
- 37. Being gay made everything much more difficult, and contributed to my decision not to be open about my infection with HCV. People would have thought it was because of all the wrong reasons. The stigma around HIV had moved on a little bit at the time, but it was still around. I therefore kept the diagnosis to myself, unless I had to.

- 38. Every time I went to have blood taken, I recall the nurses double gloving. I also had trouble with receiving dental care. They were not happy about treating me, so would refer me on as much as they could. It was not a nice way to be treated.
- 39. At the time I was diagnosed, I was worried about being a HCV positive nurse. No one at that time knew what limitations the virus would put on your career. I had regular interviews with occupational health. It certainly closed a number of avenues including acute nursing, which I loved. As a deputy ward manager, it was easier for me to avoid certain work, but in the end I decided to take a role doing more community based work.
- 40. As there were issues over time off work, I ended up telling a few bosses about my HCV status. Not everyone on the ward knew, but I felt compelled to tell someone in case anything happened at work. They were very understanding, perhaps because of the NHS environment.
- 41. Due to the issues surrounding AIDS at the time, I made sure I told people exactly how I contracted HCV. Being gay I did not want them to suspect otherwise.
- 42. I decided to give up on my career because I was told the treatment was unlikely to work and, as a nurse knew the implications of liver disease. At this point I was an 'H stage' senior nurse manager, and in the process of leadership training. I was on track to be a Director of Nursing in another few years.
- 43. When my partner and I came back to the UK in 2007, my nurse registration had expired. In total I had not practiced for a period of 4 and a half years, which was damaging to my career. I decided to do the 'back to practice course', and worked as a staff nurse on a stroke unit from 2008 until I retired a few months ago. I was very fortunate to

have been accepted onto the 3-month course, as they were not running often at that time. It was a huge step back in my career; being in a junior role but with extensive knowledge and experience. There were often situations where I would have to bite my tongue.

- 44. I have two NHS pensions, the first being frozen when I left work and moved to Spain. I had to restart under a new pension scheme, and consequently they are less than they would have been had I not given up on my career.
- 45. Despite clearing the virus, I still struggle with travel insurance cover. Each provider will ask about pre-existing medical conditions, where I declare that I have Von Willebrand's disease. They then go on to ask whether I developed HCV, and also enquire about liver disease. I am either faced with a huge premium or not covered at all.
- 46. Being infected with HCV also had an impact on my partner. When I was first diagnosed he was very concerned about my life expectancy.

Section 6. Treatment/Care/Support

- 47. I did not face any difficulties in receiving treatment.
- 48. I did not seek any counselling, and as far as I know it was not available, except for the sessions at Addenbrooks as part of the HIV screening process.

Section 7. Financial Assistance

- 49. It was my mother who saw something about the Skipton Fund on the television and notified me.
- I consequently got in touch with the Skipton Fund. They contacted Addenbrookes for evidence that I received blood products.

- 51. I was awarded a lump sum payment of £20,000 in September 2007.
- I also receive the Stage 1 monthly payments, which are £330. I am very grateful for these payments.
- It did cross my mind to apply for Stage 2 payments, but after speaking with the Skipton Fund it is clear I will not get anything.
- 54. I have always felt that there should be something discretionary for those in my situation. I count myself lucky to have cleared the virus, and that my liver has recovered, but the infection still had a major impact on my life. I was diagnosed at a time when it was very different and support was non-existent.

Section 8. Other Issues

- 55. I do sometimes feel resentful that simply because I contracted the disease, was treated and cleared the virus, that is it. It is implied that I should now get on with it. This is wrong; I still have the worry that the virus will come back.
- 56. People in my situation should be entitled to have the effect of HCV on our lives taken into account, as those who go on to develop liver disease do. I do not think this has been done at all. I am aggrieved that we are the forgotten people.

Statement of Truth

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

GRO-C Signed ____

Dated 13 - 02 - 2019.