Witness Name: Paul Desmond
Statement No.: WITN0479001
Exhibits: NOT RELEVANT
WITN0479003
Dated: 11 December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAUL DESMOND

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12th October 2018.

I, Paul Desmond, will say as follows:

Introduction

1. My name is Paul Desmond. My date of birth and address are known to the Inquiry.

2. I am the CEO of The Hepatitis B Positive Trust.

3. I am not married.

4. I intend to speak about my life and how I came to be infected with the Hepatitis C Virus (HCV).

5. In particular, I will go into details on how the contamination has impacted on my general health and wellbeing and how the illness has affected my life.

6. I have been asked if I am currently legally represented, the answer is no.

7. I am content for my statement to be taken by the investigators from the Inquiry.

How Infected

8. I was infected with the Hepatitis C virus (HCV) in 1979 through several needle stick injuries while tidying up after heroin users, in London.

Background

9. During summer 1979 I was doing an apprenticeship at Unilever and I was living in GRO-C in North West London sharing a two bedroom flat with a former schoolmate (we were about 18) and his pregnant girlfriend. GRO-C GRO-C GRO-C and then a lot of heroin addicts started to come to the flat.

10. Around June 1979 while I was cleaning up the flat I experienced several needle stick injuries. There were needles left in the sink in a pond of dirty water, needles on the floor, and needles down the back of the settee. I have no idea how many times I got needle sticks but I clearly remember many. After that episode I left the flat and I went back home to my family.

11. About two months afterwards I started to feel unwell and to have the symptoms that nowadays I know are recognised as the symptoms of Hepatitis C. I went brilliant yellow, my eyes were dark brown, my pee was black and my poo was white. I was extremely tired (I could sit in a chair for 24 hours without doing anything) and I couldn't eat at all for days. I could feel that my liver was painful. I had encephalitis and hallucinations.

12. Around October 1979 I was extremely ill and I went to the GP (it took me 2 hours to walk to her surgery nearby). She understood that I was in a critical condition and she immediately called an ambulance. They brought me to the Northwick Park Hospital in Harrow and I was put in the isolation unit very quickly. I stayed there possibly for a week but I don't remember very well. I clearly remember that I had very abnormal liver readings and that I was hallucinating.

13. At first the doctors had no idea of what was happening to my body: they told me that I could either have a non-Hodgkin's lymphoma or a liver cancer or that I might have a mysterious virus. After some tests they excluded the first two options and they thought I had an unknown virus.

14. I remember that they also told me that I had Hepatitis, but they didn't specify which type and they just said it very quickly without giving any detail. So I left the hospital (I believe that I actually discharged myself) and it took me 7 months to recover.

15. From late 1980 I was fine, no one did any further test or further analysis. My life simply went back to normality and I didn't think about it for the following 26 years.

16. In 1994 I read a note on the 'John Lloyd' outside cover of my medical records **"Non A and Non B???"** was written. I had no idea what it meant and I didn't think about it too much at that time.

17. From 1999 the GP had prescribed paracetamol for my agony headaches every year, often a box a day, between 12 and 20 tablets a day; that medication helped destroyed my liver. I remember that the paracetamol was making me bleed from the nose and the back. Obviously I questioned the GP whether that was OK and he carried on with paracetamol, avoiding using the proper medicine to save money.

18. A symptom related to the mysterious virus Non A and Non B (Hepatitis C) was gallstones, which were diagnosed in 2004.

19. By 2005 I went back to my GP and I told him that I felt the same hepatitis type pain I had in 1979. That day I also noticed again on my medical notes there was still written **"Non A and Non B???"** (this photocopy is filed by me and is exhibited as **WITN0479003**) I didn't say anything to the GP but after I made some searches.

20. The GP sent me for some liver scan/ultrasound and they confirmed the gallstones. The specialists told me that I need a gallstone surgery. Before the surgery the doctors ran some tests (checking whether I had problems with blood clotting) and they found that my liver reading was wrong, with 11 platelets and high alts. Despite that, they still wanted me to undergo the surgery.

21. Just before the surgery, I explicitly asked the surgeon and the surgical team at Northwick Park Hospital whether their approach was safe and whether the surgery would harm my liver and could they do a HCV test first. The surgeon said he couldn't make further tests. I remember one of the surgeons said that I may have **"a bit of Hep C"** but that I didn't have to worry about it. I do not know the names of who did my gall bladder surgery, just the "Blue Team" was mentioned.

22. Later that week, while I was in a local pub for a quiz night I mentioned I had a bit of HCV and a player at my table told me that his wife, a staff nurse, died of liver cancer caused by Hepatitis C.

23. Another player at the table mentioned that her brother was having a bucket of gore drained from his ascites on a weekly basis, because of Hepatitis C.

24. A friend of mine an insurance man, told me that in my condition, with **"a bit of Hep C"** no insurance company would have given me; even a 6 months loan. It was a rather surreal; the doctors were telling me, **"a bit of Hep C"** yet talking about a **serious killer** of people.

25. In the end I underwent surgery in October 2005. After the surgery my liver started to fail and I went yellow. I decided to discharge myself: I wanted to go home, exactly what I had feared was happening, surgery had made me worse.

26. I later had a Hep C test, liver scan and liver blood tests. A couple of days after the tests, on the 24th December 2005 I received a letter saying that I had Hepatitis C, cirrhosis, necrosis and dysphasia of the liver. With the same post I also received a second letter where they told me that I had a type of skin cancer called basal cell carcinoma. What a great Christmas gift, I thought. The letters advised and appointed me to see a skin cancer specialist and a liver specialist.

27. At this point I demanded to look at my GP records. I went back to the GP and questioned him why for 25 years he never noticed/reacted to the note on my medical records **"Non A and Non B???"**. He replied saying that I shouldn't try to read my notes upside down. He told me that I had a bit of Hepatitis A in 1997 and after that stated the note had disappeared.

28. In early 2006 I went to see a gastroenterologist at Northwick Park Hospital. He prescribed me a month treatment of Interferon infections and Ribavirin tablets (I started it in July).

29. The specialist told me that he would have tested me once a month only. I was aware that at St. Mary's Hospital in Paddington they would have tested every week. The specialist also warned me that it would be a very strong and difficult treatment and that the last two patients he gave this treatment to committed suicide.

30. Looking for some answers I rang the Hep C Trust and when I told them that during my treatment I was tested only once a month the head of the help line, told me that was not a normal procedure and that it could have been dangerous for me.

31. The treatment turned out to be as awful as they told me. Very quickly I went blind, I could only see blacks and whites. I immediately went to A&E at Northwick Park Hospital and they told me that they couldn't help me and that I should have waited 3 weeks to meet my specialist. The help line at the Hep C trust suggested me to throw away the treatments and to wait to meet my specialist again. I did the treatment for about 2 weeks and then I stopped: it was unbearable.

32. In the meantime I still suffered of cluster headaches. I couldn't take any medications because, as mentioned above, the GP denied me the injections to manage them.

33. Around June 2007 I decided that a private consultant could help me. So I met a Professor at the London Bridge Hospital. He said that I was at death's door: in his opinion I had to get rid of the Hepatitis C and to do that I should restart the therapy.

34. He suggested that I should approach the treatment thinking to try for even 6 months with a supply of Sumantripans at the ready. This would help me to face the extreme pain of the cluster headaches.

35. In March 2007 I went back to my GP and he referred me to Central Middlesex Hospital. Unfortunately there were no funds to be treated there. So the GP referred me to a specialist in St. Mary's Hospital in Paddington.

36. They immediately wrote to my new GP and to the Institute of Neurology saying that I needed the Sumantripan injections to manage the cluster headaches in order to later start the HCV treatment.

37. Thanks to them, I obtained the injections of Sumatriptan succinate (which cost £2,000): From September 2007 I started the treatment, and quit in February 2008. The headaches restarted in October and accompanied me for the whole period.

38. The specialists strongly advised me to undergo some further 6 months but I refused. The March 2008 Commons Seminar was coming up and I needed to be capable of running it. The treatment worked and I was SVR of HCV by July 2008.

39. In June 2008 I went for a brain scan and they told me that there was no evidence of any recent brain micro bleed but they confirmed that my brain did actually bleed during treatment.

Other Infections

40. Other than the above I have never had any other blood borne infection.

41. Before I was infected in 1979 I never had tattoos or piercings, I never used drugs or needles and I never had neither transfusions, nor surgeries.

42. I drank alcohol from 1996 to 2002 and from 2002 I am tee total.

Consent

43. As far as I am aware I have always been tested with my consent. I confirm that nothing was done without my consent.

44. In relation to consent, when I asked about the **Non A and Non B** notes on my records, I found out that the GP was hiding then destroying them, without telling me what was written honestly.

45. The GP thought that I was an alcoholic, during an appointment a GP actually told me regarding my poor liver tests "Look Paul this is because you are a drinker". That comment shocked me and I found it offensive, they were assuming alcoholism, I was approaching dying of Non A and Non B Hepatitis and they were hallucinating alcoholism instead of reading my notes for 25 years!

46. In 2005/6 I had 20 minutes to view my records and to make a copy of the 1979 "hepatitis?" note surviving. I decided to use the note to raise a claim of medical negligence at the Ombudsman.

Impact

47. In relation to the two initial failed treatments I had in 2005/6, I can honestly say that that was not a nice period at all, there was a real fear these idiotic mistakes by doctors may kill me.

48. However when I am diagnosed with something like that, I feet a 90% inspired state to manage, while the remaining 10% was real irritation with the failings of my doctors and desire to improve them.

49. I was more depressed and pained by the headaches. When you have cluster headaches you don't feel too much about a thing like HCV.

50. During the last two months of the Oct 2007 to Feb 2008 treatment I had stroke like symptoms (I couldn't lift my left arm, I was wobbly, the left side of my face dropped, my speech slurred and I had to drag my left leg).

51. Over the 3 years of the treatments I had chemo type of effects, my face gained wrinkles of pain, and my hair went grey. I also developed rheumatism, it felt like in few months I aged a decade. I had 'brain fog' and the neurological damage that the treatment gave me. I was a zombie at the end of treatment. When you take Interferon and Ribavirin you realise how these medicines really burn your body.

52. I wanted to change this condition; not being able to argue, to debate, losing my thread when interrupted, at the end of the day it was my problem and I had to solve it. At my most ill I thought that if I survived I would have opened a Charity

53. At present my leg and arm are still weak and sometimes I cannot trust them very well. I am still very sensitive to light and shiny things, they bother me; there is often an extreme photophobia that the treatment has left me with.

54. I had to re build my body, with tai chi, sport, diet and mental therapies. I literally started what I called "Liver friendly lifestyle" to be able to cure myself from all the side effects. I have always been vegetarian but I went into a toxin free diet, eating a lot of greens to build the liver, becoming tee total and being very careful with eating and lifestyle. My liver functions improved but I kept doing scans and tests at St. Mary's Hospital for several years.

55. Even now when a helpline caller patients weeps or thanks me on the phone, the idea that overcoming my cirrhosis/HCV helps me be better at helping others makes me feel a better person and charity head. What I went through helps me to truly make a difference to the just diagnosed thousands who have rung. At the end of the day I emerged a better more useful person.

56. Hepatitis C stigmatised me also from the social point of view. On my birthday (probably the 44th), I went down to the pub to celebrate with friend. Everybody knew that I had Hepatitis C. But I remember that when I kissed someone (probably because someone brought me a gift), a guy, out of the blue, punched me asking me whether I was crazy risking to infect somebody in that way. It's incredible how people are not informed in relation to HCV. Doctors would often ask are you still using heroin.

57. Before I found out that I was infected I was selling radio adverts and I was very good at it; it was a very lucrative job. One of the big drawbacks that hit me in 2008 is that I needed to earn money and I wanted to go back to that work but I was not good at selling things anymore. I couldn't go back as I didn't have that set of skills anymore. I couldn't speak enough anymore. I was not organised enough and it took me 2-3 years to recover. The cluster headaches prevented me to do anything for very long periods of times.

58. Financially, I was on the floor, I was surviving with what I have saved in the years before. Between 2005 – 2008, I didn't earn a penny.

59. In 2005 my partner left as she was obsessive about HCV infection risks, the explanation to her of her risk was brutal.

Treatment/Care/Support

60. Apart from one of the specialists at Northwick Park Hospital and Central Middlesex, all the other specialists who treated me were fine. My GP lied and destroyed my notes and assumed I was an alcoholic, so my initial experience with my treatment was dreadful. This attitude led to them repeatedly rejecting my requests for the injections to manage my headaches, leaving me unable to get treated.

61. In relation to counselling or psychological support, I had a lot of chats with the head of the help line at the Hep C trust but otherwise I have never been offered or wanted any counselling.

62. The information I got was a dreadful leaflet in 2005. NOT RELEVANT NOT RELEVANT it seems designed for criminal idiots and explains almost nothing!

63. What I am giving to the people I talk to everyday is what I would have liked to receive at that time. I had to qualify in Treating Testing and Diagnosing HBV and HCV and start teaching the GP's.

Financial Assistance

64. I am a needle stick infected person so I do not qualify for the ex gratia kind of assistance. But I do feel that there is a deserving case for those diagnosed 'non a and non b' who were and are left to die for decades untested to get some help.

Other Issues

65. In relation to the issues covered in the Rule 9 under topic 8 titled "Other issues", I will deal with them in a separate statement.

Statement of Truth

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

Signed __Paul Desmond GRO-C

Dated 11 December 2018