Witness Name: Luke Timothy O'Shea Phillips
Statement No: WITN1696001
Exhibits: WITN1696002-8
Dated: May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LUKE TIMOTHY O'SHEA PHILLIPS

I, Luke Timothy O'Shea Phillips will say as follows:-

Section 1. Introduction

1. My name is Luke Timothy O'Shea Phillips, DOB GRO-C 1981, and I live at GRO-C GRO-C with my wife and daughter.

2. I was infected with Hepatitis C after being treated with contaminated Factor VIII concentrate.

3. My mother has also provided a statement to the Inquiry.

4. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

5. I was diagnosed with mild Haemophilia A when I was one year old. My family has a history of haemophilia so it was not a big surprise when I was diagnosed.

6. We moved from Brighton to London when I was a baby and my care was transferred to the Middlesex Hospital (now the University College London) under Professor Machin.

7. In the late 1980s/early 1990s my care was transferred to Hammersmith Hospital.

8. I first received Factor VIII on 15.05.1985 following a mouth bleed. My mother did not receive any information about the products that were being used on me nor was there a discussion about the potential risk of infections.

9. It is clear from my records that I was tested for HIV (then HTLV III) in early June 1985, shortly after I was given Factor VIII. The results are now shown to me marked **WITN1696002.** Fortunately I tested negative but again, neither my mother nor I were informed that I was being tested and consequently we were not informed of the result either.

10. It also appears that I was tested for a number of viruses before I received any Factor VIII treatment. There is now shown to me marked **WITN1696003** pathology results dated 13.11.1984. It should be noted that the reason for the tests is listed as "URGENT, Haemophilia. Has received no blood products."

11. In a letter dated 12.06.1985 Professor Machin wrote to Dr Kernoff at the Royal Free Hospital and referred to my treatment with Factor VIII concentrate. In this letter he confirmed I was treated with 1,680 units of alpha heat treated Factor VIII concentrate and that I was a virgin haemophiliac (ie. I had never previously received blood products). The letter confirms that I received Profilate List Number 360210, Lot Number A6-0311 and that I was to be followed up fortnightly for liver function tests, blood count and virology. He

finished by saying *"I hope they will be suitable for the heat treated trial."* A copy of this letter is now shown to me marked **WITN1696004**.

12. The heat treated trial was not discussed with me or my mother. I also note that this letter was copied to Ian Marshall at Alpha Therapeutics. As more evidence and knowledge about the scandal became clear to me this letter for the first time became very relevant to me, about 6 months ago. I obtained copies of my records in 2004 however until further information came to light much of my records meant little to me. I've been in the dark for years..

13. The first time I remember having an HIV test was when I was 13 or 14 and going to Hammersmith Hospital. They made it seem that it was standard practice I would be tested for HIV. I was not told of any reason why I required the test. The Hammersmith team were my haematology team and I trusted them with my life so I didn't question it. I don't remember ever being told the result. I don't believe I received a letter or anything. Now of course I know why I was being tested but back then I didn't know anything.

14. There is a letter in my records dated 22.06.1993 from Professor Machin to Ealing Health Authority which confirms that I was HIV negative and had normal liver function tests at that time. It also confirms that I had only required treatment with Factor VIII on one or two occasions a year since 1985. A copy of this letter is now shown to me marked **WITN1696005.**

15. My mother received a letter on 06.01.1997 that read *"you will remember that Luke has acquired Hepatitis C infection at some time in the past".* This was the first time she was made aware of my infection. A copy of this letter is now shown to me marked **WITN1696006.** According to my records I tested positive for Hepatitis C antibodies on 29.04 93. A copy of my test result is exhibited at **WITN1696007.** I am not sure whether this is the first time that I tested positive or whether there might be earlier test results.

16. There are several earlier references in my records to the fact that Hammersmith Hospital was aware I had tested positive for Hepatitis C and

that I and my family were unaware of this. The relevant documents are exhibited at **WITN1696008.**

17. A few days after my mum received the letter stating I had Hepatitis C she took me to see Dr Laffan at the Hammersmith Hospital. Dr Laffan told me that I had been infected with Hepatitis C and he explained the condition to me and I believe arranged for me to see a specialist. This part of my life is a blur due to the pain and disbelief that I was feeling.

18. I remember Mum told me on the way to the hospital what had happened and Dr Laffan then confirmed what she had told me. It was all too much for me to deal with at the time so I don't have a great recollection of the appointment itself.

19. A few weeks later I went to the Hepatitis C clinic and, at that time, was told there was no treatment because the strain of Hepatitis C I had was such that Interferon would have a very small chance of clearing it.

Section 3. Other Infections

20. vCJD was not discussed with me in detail. I remember that there was some talk about it when I was younger but this was from other people not the hospital. I don't recall being notified that I was at risk of vCJD. However, I can't be 100% certain, I was a teenager dealing with a Hepatitis C diagnosis.

Section 4. Consent

21. Neither my mother nor I were aware that I was being tested for Hepatitis C or HIV. My mother was made to believe that the blood tests were just routine tests related to my haemophilia.

22. In my medical records there at least 2 references to the fact that neither my mother nor I were informed when I first tested positive for Hepatitis. C.

23. Given the letters/notes in my medical records referred to above I believe that I was treated and tested for the purposes of research because I was a Previously Untreated Patient (PUP).

Section 5. Impact of the Infection

24. I have struggled with my mental health since I was diagnosed, I found relationships difficult and I struggled to trust people. I was infected so young that I don't know what life would have been like if this had never happened to me. This also means that describing physical effects is also difficult because I've never really known 'normal'. I have been tired and stressed my entire life.

25. My infection tainted so many of my decisions between the ages of 16 and 23 because I was told that there was only a 30-40% chance of any treatment working. I felt that there was no hope of a cure.

26. I couldn't drink because of my infection which I felt excluded me in social situations. I was young and wanted to go to university to study but after my diagnosis I completely lost confidence and I struggled with my education. I didn't care anymore once I found out about my diagnosis and all of my dreams of university and a meaningful career were smashed. I therefore stopped trying at school. I only got 2 A-levels from college and this has had a significant detrimental impact on my working life.

27. I felt like I was a walking infection machine; I was terrified I would infect others and this destroyed my private life. I have a half brother and sister younger than me, I would see them at school holidays, they were put at risk, I have struggled with relationships and even when I cleared the virus I remained terrified that I was not actually clear or that the virus would return. When I eventually met my wife it was a very difficult conversation for me to tell her about my infection, but fortunately she was very understanding. It was hard as her family took a long time to accept my medical conditions.

28. I find it all very difficult to talk about. I was horrible to my family and friends I didn't blamed my Mum for what happened to me, I felt I had let her down and wasn't an adequate son for her I know the pain they felt now and I know it ruined my Mum's life. I hated my life and everyone in it I hated myself. I felt dirty so I just couldn't tell anyone outside my closest circle, I was afraid of being treated like scum, I felt like scum.

29. I received treatment with Interferon and Ribavirin in 2004 in an attempt to clear the virus. It was so difficult and I don't think I've been the same since. Again as I was young, its hard to describe the changes, however I can only really say I've been in a mental fog my whole life and the treatment left me traumatised.

30. At the time of my treatment I was employed by the BBC (as I continue to be today). They supported me through my treatment. I was very ill for the duration of the 11 months of treatment; it was like having the worst flu ever. I lived with my mum and she did everything for me, I couldn't cope without her incredible support I was permanently tired and I needed to take time off work, however I did everything I could to attend. I was only a 23/4 year old man. I wasn't able to have a social life, I was stuck indoors, I missed out on so much and this has affected me every day since. I had everything taken away from me

31. There was a 6 month recovery time following the treatment. The BBC put me on light duties. Mum would take me to work and bring me back. She cooked for me every single night. I couldn't go out or do anything in a normal way, I did the best I could and everyday was a battle. One friend would have me over once a month to play computer games and have a Chinese and that was the absolute highlight of that time for me. I completely missed out of my youth because of my infection.

32. The treatment was hard on my mind, body and family. . Before that I liked clean living and had only taken antibiotics on one previous occasion. I tried to maintain some normality but it was hard. I had acupuncture throughout the treatment and I think that saved me.

33. My white blood cell count was very low so I was in an out of hospital. I couldn't go to crowded places. There were unpleasant side effects but the mental impact was by far the worst aspect. I couldn't think straight or make decisions about things. I lost my sense of self and it took a long time to get over that.

34. I got better and the treatment was successful but I am still left with fear of the Hepatitis C coming back. That fear is still there all the time. It terrifies me.

35. After my treatment I was so angry and I went off the rails. I was horrible to my family. I was a terrible person. This carried on for 3 to 4 years and I didn't even know why I was doing it. People said that I was so lucky to be better but I didn't feel lucky. I still, don't feel lucky – nobody would want my luck of being treated with infected blood products at the age of 4 and contracting Hepatitis C which I then wasn't told about until 1997.

36. People have short memories. They quickly forget what you've been through. I still panic every night that the Hepatitis C will come back or something I do will bring it back.

37. The treatment was a further trauma and I've never been able to get over it. When you have Hepatitis C you know what you need to do to look after yourself. I didn't drink. I looked after myself. I read as much as I could about it and tried things like Chinese medicine and drinking cranberry juice. The treatment was an unknown.

38. I decided to have my treatment at Chelsea & Westminster Hospital and put myself in with those who had contracted Hepatitis C through taking drugs. I wanted to control my treatment. I'd had enough done to me and it was important to me to take control back.

39. I'm happy I took control and that decision. At that time I didn't want to be around other haemophiliacs and the other misery stories. I wanted to meet different people and learn from them. I met some amazing recovering

addicts. Some were so inspirational. We talked about what we would do when we were better rather than talking about haemophilia and Hepatitis C.

40. I didn't have a clue how much the treatment would affect me short and long term. When the letter came which told me I had cleared Hepatitis C – it took me a week to open it. I had no support to help me deal with the news. It sounds odd because it was obviously good news but I had been ill for so long and lived with Hepatitis C for so long that it was a massive adjustment to be told I had cleared it.

41. I have done okay at work, having worked for the BBC for 17 years now, but it still makes me incredibly angry as I know I could have been so much more; I could have been anything I wanted, I had all my ambition, energy, drive and passion taken from me. This meant I haven't achieved anywhere near my potential.

42. I've never succumbed or given up or given in. I have tried to do as much as I possibly can and not be depressed about it and not let it affect my life. I didn't want to let those who infected me win. My Mum always brought me up to look forward and move forward and that is what I have spent my life trying to do but it is hard and it takes work.

43. Sometimes I also feel guilty about how this scandal has affected others. I feel guilty for not being as ill as other people.

44. However, I feel that I don't have 60% of myself. At least 60% of my life has been taken up thinking about contaminated blood and Hepatitis C. Even if I've achieved good things I always struggle to think what I could have done on 100%. I was so young when this happened – it took my confidence. It made me feel worthless that I could be given these viruses as a child. I now have to live with this and I've always had it and it's never been any different.

45. I worry a time will come when it will take control and get on top of me. I battle my depression. I don't want it to ruin my life but the energy it takes to fight it

is intense. It takes energy to talk about normal things and not let what has happened define me and be the focus of my life.

46. I was only a child. I am angry. No child should be put through this.

47. I met my wife about 12 years ago and we got together 7 years ago. We have been married about 4 years. She is very strong. She understands me and what I've been through. It is not the thing that defines who we are or what our life is about. We live a normal life but it takes work to do it.

48. I now have a daughter and I also worry that what I have been through will affect me being a good father.

Section 6. Treatment/care/support

49. I was not offered any support when I was informed of my diagnosis as a teenager and the only counselling I have ever received I had to arrange by myself. This only came around when I went to Dr Laffan in 2017 and told him about everything I had been through. By the time I received any counselling I was 36 years old; 21 years after I was first diagnosed.

50. Dr Laffan referred me to Lewisham Council's self diagnosis mental health portal and I had to self refer. Within 8 weeks I had a counsellor but I was only offered 8 weeks of counselling because that is the NHS limit. I committed myself fully to make the most of it but I do think that being offered 8 sessions for 45 minutes after 34 years of having to deal with this is unacceptable.

Section 7. Financial Assistance

51. I received the Skipton Stage One Payment about 15 years ago.

52. I currently receive regular payment through EIBSS. I had to see my haemophilia consultant on a number of occasions and he wrote a letter recommending that I be moved to the higher level of payment

53. I feel like I have been made to beg by the various financial assistance schemes and somehow prove I am suffering. This is not easy for me to do as I have spent the last 20 years pretending it is all okay.

Section 8. Other Issues

54. I want to be able to say, no matter how hard you try you will not knock me down. I will keep going forever. I feel they tried to kill me and wipe me out but somehow I have survived.

55. This Inquiry is not a magic fix. I still have to live with myself but I do want them to get to the truth of what happened and why. I want to tell my story.

Anonymity

56. I do not want to apply for anonymity and understand that my statement will be published as part of the Inquiry.

57. I would like to give oral evidence.

Statement of Truth

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

Signed GRO-C

Dated 22/MAY/2019