Witness Name: Phillip James Wheeler
Statement No: WITN 1602001
Exhibits: 0
Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PHILLIP JAMES WHEELER

I, Phillip James Wheeler, will say as follows:-

Section 1. Introduction

1. My name is Phillip James Wheeler. My date of birth is GRO-C 1979. I am a single person and I live at GRO-C. I have one sibling, an older sister GRO-C.

2. I was infected with Hepatitis C as a result of treatment Factor VIII (FVIII) that was contaminated.

3. This witness statement has been prepared without the benefit of access to my medical records.

Section 2. How Infected

4. I understand that haemophilia has been on my mother's side of the family for generations. GRO-C. My cousin, Colin, and I were one of the first members of the family to be diagnosed with the disorder. Colin died of AIDS at the age of 7.

5. I was about six months old when I was diagnosed with severe haemophilia A.

6. In the 1980's, I was treated at Great Ormand Street Hospital (the "hospital") in London and at St Peters Haemophilic Centre in Chertsey (Haemophiliac Centre). At the hospital, I was under the care of a lady whom I called "Kate" and at Haemophilic Centre I was under the care of Dr Newton.

7. I was treated with different Factor VIII (FVIII) products. My parents were shown how to treat me at home when I was 3 years old and, when they became familiar with the process, they were able to collect 3 to 4 months supply of these products from the hospital. I know my parents sometimes collected these products from the Haemophilic Centre when they ran out of supply and were unable to travel to the hospital. My mother remembers that one of the products collected from the hospital was called Alpha.

8. As an active child, I suffered from bleeds at least once a week. For this reason, the doctors moved me onto Prophylaxis when I was aged 6 or 7. They were told this product prevented bleeds rather than stop them.

9. I was moved from one product to another and the hospital explained this was due to better and more effective products coming onto the market. I did not have any side effects from any of the products and I think the NHS was trying to find the cheapest option to treat me. I was aged about 8 or 9 when we found about the risks of AIDS to haemophiliacs that my mother and I met Dr. Newton at St. Peters hospital in Chertsey. My parents and I bot remember Dr. Newton as an excellent paediatrician and thought very highly of him. He said *"..we need to get Phillip off UK products and onto American heated products as soon as possible because of the danger of infection from AIDS.."* My mother was both very worried and apprehensive and she questioned Dr. Newton and he clearly told her *"..change of product is the right move as we wouldn't want Phillip getting shot of the last day of the war.."*

10. It was in and about 1989, when I was aged about 9, the hospital informed my parents that my liver was not functioning normally but they did not elaborate upon this. As a result my parents began to speak with other parents at the hospital and found out that they too were being similarly advised about their own children.

11. It was in about June 1990, the doctors informed my parents that I was infected. It was Kate from the hospital who saw my parents at their house to advise them of this. My mother explicitly remembers Kate informing her that my liver function tests were serious and that they were going to put me on a new drug to treat the infection. Kate told us I had non A non B hepatitis but at no point did she mention hepatitis C.

12. The hospital advised my parents that it was more important to have FVIII products in my body regardless of the situation (ie even if they were unsafe) and that the risks were worth it. I knew Colin was treated with similar blood products to me and because the doctors failed to keep us informed, there was a growing panic that I too had contracted HIV.

13. After Colin died, I was petrified and I became more inquisitive. I remember asking nurses at the hospital whether *"I would catch what had Colin got".* The nurses explained to me in a child friendly way how blood products were made. I already knew that blood came from people and that infected blood would be passed on. I was aged about 11 or 12 when I was told I was lucky because the doctors had decided to move me onto a better product and that there was no longer a risk of being infected.

14. The doctors led me to believe that this new product was much better than the products previously used because the blood came from Russian rats rather than people and carried no risk of infection. I am not sure whether this was true or whether it was to put my mind at ease.

15. The hospital staff, my parents and I openly discussed how Colin died. It was accepted that he had been infected as a result of the blood products used to treat him. However, the hospital did try to defend itself by stating that his death was *"..a one off tragedy.."* and that it was not liable because it was not aware of the risks involved with the products.

16. The hepatitis C infection caused me to have terrible flu-like symptoms. After a little while, my parents figured out that these symptoms took effect seven hours after I was given the injections. For this reason, the injections were given to me late

afternoon so I would sleep through the effect of the treatment. Eventually, I got used to the injections, but at the beginning I missed a lot of sleep.

17. Despite assurances given to me, I was scared because I had lost my confidence with the hospital and convinced that the products used to treat me were unsafe. I was worried that I was going to follow the same path as Colin. For this reason, I started to doubt whatever I was told by the nurses and I even doubted my own parents. I was not sure whether they were just being nice to me and did not want me to worry. I remember that throughout this uncertain period, I thought I was going to die.

18. Before Mary came to visit my parents in 1990, the hospital had told my mother that my liver was not functionally normally. My mother attempted to obtain further information but to no avail. My parents felt that the hospital were not helpful. They were only told that I was suffering from a new disease and was to be given a new drug to treat it. I later found for myself this new drug was called "Interferon"

19. I believe my parents should have been told about my infection earlier. The hospital knew that I was at risk of an infection for a long time, hence the liver test. I am also of a firm belief the hospital knew in 1987 - 1988 more than what it was prepared to disclose to us at that time.

20. I first learnt about Hepatitis C when I was being treated with Interferon at the hospital. Interferon was new to the market and was being used to see whether it could clear the infection. I must have been either 9 or 10 years old when I was told that I had scar tissue on my liver and was not functioning normally. I recall someone in the hospital saying that I could live for another 30 years and being made upset by such comments.

21. I was told that I was lucky because I was one of the first 10,000 people to be treated with Interferon. I remember the doctors did not appear to show much optimism that it would be effective.

22. I was about 10 or 11 when the hospital were treating me with the American products (not from human donor) for haemophilia and Interferon for the infection. At the time I was really upset because the doctors told me that I needed three Interferon

injections a week and this was on top of the haemophilia injections. I hated injecting myself in general; I just wanted to be normal like everyone else.

23. The hospital's general attitude was just for us to get on with it and live our lives. We were never given any reassurances that Interferon would work. It was my parents who had to chase the hospital for information.

Section 3. Other Infections.

24. As far as I am aware I have not contracted any other infections from the blood products given to me by the NHS.

Section 4. Consent.

25. I was always treated and tested with my parents' consent. We placed utmost trust in the hospital, but we were not told the blood products used to treat me were contaminated.

26. I underwent blood tests and these were carried out with my parents' consent. However, I was never told what my blood was being tested for.

Section 5. Impact

27. When the doctors informed me that I was infected by contaminated blood, I assumed I was HIV and that I was going to die. The hospital failed to provide any further information about this and what further treatment it had planned for me. Needless to say, this was very traumatic for me as a young boy at the time.

28. I believe Colin's death shaped my life. The fact that we both suffered from haemophilia brought us really close. His death forced me to prepare myself with death really early on in life.

29. When Colin died, I was not allowed to go to his funeral because my parents thought I was too young. I was devastated, I desperately wanted to say goodbye to him.

Primary School

30. I used to be more of an extrovert always playing in a playground with friends, but the worries in relation to the Hepatitis and the loss my cousin had an adverse effect on me. I did not know whether I was going to live and if so, how long for. I think I became quite depressed.

31. At school I was always really honest with my friends about my condition and told them that my cousin suffered from HIV. After he died, I had to take some time off school because I struggled to cope. Upon returning, I found out that some children accused me of lying and I was bullied for some time. This experience made me quieter.

32. I felt isolated at school. I was the only child who suffered from haemophilia in both primary and secondary schools so I was subjected to discrimination. This came from both teachers and parents. For example, some of the children told me that they would not share can of drink with me because their parents told them not to.

33. There was also an unkind dinner lady that would tell other students not to play with me. The teachers were mostly wary, they would not allow me to mess about with other children or play contact sports in case I hurt myself.

34. There were some extreme cases, for example at school we had a fish tank and I would be the only child not allowed to feed the fish in case I was to cut myself on the glass of the fish tank. The comments from other children would always hurt because my family and I knew that this came from parents and not the other children.

35. I had no interest in learning, I just wanted to play with my friends and enjoy whatever life I had left. I struggled with illnesses from birth and I remember being told that I will not live past 40. I was tired and unfocused. I also had to take some time off school. Unfortunately, I was put on Interferon during an important time at school. I was completing key stage 3 and was between primary and secondary school. This really affected my results at school.

Secondary School

36. I struggled to fit in at secondary school. My GCSE results suffered as a result and I was the only one out of my friends who did not go to university. That is one of my main regrets. I do believe a university education is likely to have created more employment opportunities for me.

37. The uncertainties made me hedonistic. I started smoking and drinking early in life, and not paid attention at school. I thought that I was cursed with just about everything and that I was set for failure.

38. My parents saw what was happening to me and asked a family friend who had counselling qualification to see me for few sessions. It took me years to rebuild my confidence to get to the point I am now.

39. In primary school I had a lot of friends that I would just kick a ball with but in the secondary school, as I got more competitive, I was not allowed to get involved. I was desperate to be a part of something, desperate for approval. I was told that I was clear of hepatitis at the age of 15 but it was too late then. I was too far gone and I built this character and reputation that was hard to get rid off. I continued that lifestyle until I started a college course at the age of 17 or 18.

40. Because I could not make friends at school in traditional ways, for example being on a sports teams I tried to get attention. I think it is important for a young person to be a part of something. For boys this is usually being a part of a sports team. I was denied that.

Employment

41. I also got my first job and that helped me focus. I do believe that if I did not contract hepatitis C I would have done better at school and had a chance to go to a university and this would have created more opportunities for me. When I was younger, I wanted to be a film critique but I needed a degree in English. For this reason, I was unable to pursue my desired career.

42. I now work for a school photography company and my role is to expand their base of customers. I have been working there for 7 years. I always worked in advertising and sales.

Relationships

43. As a result of my hepatitis infection I suffer from permanent liver damage and liver scarring. Although a test carried out recently has revealed no complications, my underlying problems are chronic and will never fully disappear.

44. Hepatitis C inevitably affects physical relationships. I do find it difficult to maintain a relationship due to my condition. I always disclose this information to potential partners and it is never an easy conversation to have. I am currently single.

45. My last girlfriend of a year and a half had no problem with it. However, I knew her mother was very concerned. It was a much more of a problem when I was younger, especially in my teens and early 20s when image is everything. I did not know how to break the information to girls I was dating but I think that over the years I got better at it. Still, people talk. I remember one girl, I must have been 15, said to me that *"I would go out with you but the haemophilia side of it worries me."* That was very painful to hear.

Family

46. I have a close connection with my family and my infection never impacted our relationship.

Section 6. Treatment/Care/Support

47. The hospital treated me with Interferon. I was warned that the drug was experimental and might not work. The treatment lasted for six to nine months and during this period I suffered considerably with flu-like symptoms.

48. I did not know how long I was going to be on Interferon for and was I told that this would depend on my liver test results. Eventually when my results improved, I came off the treatment. Even then I was told by the medical staff that I was lucky. At the time I did not really care, I just wanted to come off the treatment because the side

effects became unbearable and affected my life. At first, I had to go back to Great Ormond for check-ups every three months but now these are carried out annually.

Effect of the treatment

49. I believe that one of the main areas affected was my education, particularly the transition between primary and secondary school. Both the infection and the treatment affected my confidence and as a result I found it really hard to adapt and make friends in a new school.

50. Before the infection I had a lot of friends, I was popular at the primary school, but anxiety and the fear stopped me from being myself. I became withdrawn and depressed. I lost interest in just about anything including schoolwork.

51. It was always hard being the only haemophiliac in school because I was not allowed to play football or other contact sports in case I got ill. However, being a child with haemophilia and hepatitis created a different kind of exclusion. Despite my age, doctors were brutally honest with me and told me that the Interferon might not work. This triggered my anxiety. I was upset because I did not know what was going to happen to me. I saw my little cousin die. I had all kind of fears and was forced to process information no other child my age would. At the age of 10 I had to accept the fact that I can die very soon. It was a horrible time.

52. There was a time when I could not treat myself and this was because I had lost my confidence. I had always been good at doing my injections but after about 3 years this suddenly stopped. I gradually started getting worse at it would often miss a vein. I developed hatred towards injections and sometimes even refuse to have them altogether. I often hurt myself and my father had to inject me for a period until I regained confidence.

53. When I was 11 years old my parents separated. I started to suffer from nightmares and I could not sleep on my own. I insisted on sleeping in my mum's bed. At the time my confidence was in pieces, I was in a permanent state of unrest. I never quite knew what was wrong with me. Even when I finished the course of Interferon, the doctors never told me that I was cured. I fear that sometime in the future, I will be told that I will have to go back on it.

Present position

54. I am informed my liver is functioning at approximately 90 per cent. I still have regular check-ups but this has become incidental. For example, If I am at hospital for some reason, I may be told by nurses, "*...we have not checked your liver for a while, we should probably do that..*"

55. It has been a long time since I was declared "clear". I am 40 next year and well, despite the life expectancy prediction I was given as a child.

56. I consider I was given the adequate medical treatment for Hepatitis C. I consider Interferon has cleared the virus.

57. I consider that I could have done with some form of psychological support from the hospital. During my treatment I became quiet, withdrawn and depressed. My parents noticed it early on and found help for me privately. They got in touch with a family friend who was a teacher with counselling qualification and asked me to see her few times. I think having someone to talk to that was not family was a big relief and helped me deal with this burden I was carrying as a child. I think this help should have been provided by the NHS and given by someone who had experience with Hepatitis. But this was never offered to me. I believe my mother too should have been offered more support and some form of counselling.

Section 7. Financial Assistance

58. The only trust I was in contact with was the Skipton fund. I received a one off payment of £20,000 in either 2001 or 2002. My auntie who was also Colin's mother told my parents about the Skipton Fund and how to apply.

59. My parents took it upon themselves to make the application, so I am not sure how the process worked. I do remember my mum telling me that there was no guarantee that the money was going to be paid out.

Section 8. Other Issues

60. My mother was very proactive. She was always collecting money for the Great Ormond Street hospital and the NHS. She did Parachute jumps for charity and raffles for Haemophilia Society. I even went for few weekends away for children with haemophilia with the Society.

61. I have never got involved with any campaigns involving the haemophiliac society.

Conclusion

62. I really feel for my parents because they were always left in the unknown by the doctors. I cannot even begin to imagine the anger and hopelessness that they have felt. It was the same for my auntie who lost her son to HIV when he was only 7 years old. For years they lived in fear watching their children getting ill and not being able to do anything about it.

Anonymity, disclosure and redaction

63. I do not wish to be anonymous.

64. I am prepared to attend court to give evidence.

Statement of Truth

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

Signed…. GRO-C …..

Phillip James Wheeler

Dated 26th February 2019