Witness Name: David Whistler
Statement No: WITN1603001
Exhibits:WITN1603002 - 004
Dated: May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DAVID WHISTLER

I, David Whistler will say as follows:-

Section 1. Introduction

1. My name is David Whistler of GRO-C Gloucestershire GRO-C. I was born on the GRO-C 1971. I currently live with my wife, Valerie Whistler and I have a step daughter who is 19. I currently freelance as an IT technician.

2. As a result of receiving Factor IX (FIX) Concentrate I was infected with Hepatitis C (Hep C).

3. This witness statement has been prepared without the benefit of access to my full medical records. I have copies of my medical records however there are particular treatments I underwent and consultations I remember attending which have been omitted entirely from the records.

Section 2. How Infected

4. I was diagnosed with Haemophilia B (also known as Christmas Disease) when I was born. My grandfather suffered from Haemophilia and my mother was a carrier. I have a sister, but she is not a carrier. Although the tests state that my Haemophilia is moderate, it is temperamental and often fluctuates

between mild and severe, a fact I discovered a couple of years ago. I could do something one day and not bleed and do the same thing the next day and bleed heavily.

5. In the early 1970s, I was treated with whole blood plasma. I was later given FIX in or about the late 1970s/early 1980s. I then moved to recombinant FIX, Benefix. My Haemophilia is currently under control and I do not have any significant issues.

6. I was born in Lincolnshire and was treated at Sheffield Hospital until 18 months old. I then moved to Cornwall and I was treated at the Royal Cornwall Hospital (Truro) under the care of Dr Murrell. From the mid 1978 to September 1986, I attended Bristol Royal Hospital (BRH) for Sick Children and was under the care of Dr Burman and thereafter I was treated at the Bristol Royal Infirmary (BRI) under the care of Dr Scott. I changed three years ago to Oxford Haemophilia Centre (OHC).

7. I do not know exactly which treatment gave me the infection. When the hospital informed me about Hep C in or about 1996, they told me that they were unable to determine exactly which products had infected me. I was never informed when I was infected, however my GP records strongly suggest that I was infected between the years 1979 to 1981. During this period I suffered illness on a number of occasions, which I consider are linked to acute Hep C symptoms such as liver pain, abdominal pain, sore throats and flu. I was hospitalised for three days in May 1979 with abdominal pains and jaundice, although in my medical records there is no mention of those three days. I remember it vividly as I was put in an isolation ward and all the nurses that treated wore gowns as I was deemed highly contagious. No one was allowed to see me and the doctor joked about it and said it was a Yate bug.

8. Prior to receiving FIX I was never informed that the treatment carried a risk of infection/s. I spoke to my mother about this but she was of an era where she would not question the doctor's advice or authority and believed that anything they said or did was for my wellbeing. When questioning my mother earlier this year about what was mentioned to her at the time with regard to infected

blood risk, she said nothing was ever mentioned to her by Dr Scott or his team.

9. My mother believed the school nurse wanted to inject my FIX and so my mother refused permission. She raised the nurses' request with Dr Scott, Haematologist at the Bristol Royal Infirmary, whose reply was: "If she's that concerned tell her just to throw bleach on it".

10. This suggests to me that the medical professional (Nurse) was aware of the risk of contaminated blood to Haemophiliacs and was expressing concern. My mother was unaware of those risks and the blasé comment from Dr Scott about throwing bleach suggests to me that my mother really was not informed or advised of the risks. It was very distressing to hear such comment from a medical professional.

11. As stated above, I was infected with Hep C as a result of receiving contaminated blood products. I found a blood test record, a copy which is exhibited at **'WITN1603002'**, in my medical records which confirms that I tested positive for Hep C on the 20 May 1993. I was told at a routine appointment in 1996 that I had tested positive for Hep C. I was told by the doctors that they were not aware that the disease existed and told me that there was no treatment available, so there was a high possibility that the virus could kill me. They did not mention how I had contracted the infection. I never realised then that what they had told me was life changing as I was not given adequate information at the time. Having grown up with haemophilia, I was used to handling the condition and it became part of who I was so to me, Hep C was just another condition I had to deal with.

12. I believe that information should have been provided to me earlier. At the very least I should been given information on the risk of transmission as I was in my early twenties. Moreover, my diagnosis should have been brought to my attention earlier. I do not understand why I was not told about my test results that I had in 1993. I was never told that I would be tested for Hep C.

13. When I was told that I had Hep C, I was young and it came as such a shock, but I did not question the doctors. Instead I respected them and accepted what they said as the truth. I was given such little information in hindsight about how it would impact my life. It was only in the early 2000s that I realised how serious Hep C was. I was never told of the side-effects of the infection.

14. At later appointments, I was informed that the risk of transmitting the infection was very low. At the time I was living with my girlfriend, so such information was important for me.

15. According to my National Haemophilia Database (NHD), a copy which is exhibited at **'WITN1603003'**, it shows that I was tested for HIV in 1985 and 1987. However, my medical records confirm that I was also tested in April 1988 and 1991. Copies of the above blood test are exhibited at **'WITN1603004'**.

Section 3. Other Infections

16. In my NHD records, it states that I was notified about vCJD in 2004. I was never told that I was at risk of vCJD. I was told much later that anyone exposed to infected blood apparently had to be told they were at risk of vCJD and that if we went for dental treatment or surgery the medical professional needed to know that risk so that equipment could be destroyed after any procedures.

17. I cannot say if I have been infected with any other infections apart from Hep C, but since that was kept from me, only the doctors knows what else I might have been exposed to over the years.

Section 4. Consent

18. My medical records indicate a positive Hep C result in 1993, however I was only told in 1996 therefore I believe that I was tested for Hep C without my knowledge and consent and without being given adequate or full information.

19. I consented to the HIV tests in the 1980s and was told prior to those tests that since I had Haemophilia B and received FIX, I was at low risk of contracting HIV, but I was given regular testing for surety. Other than being told that I was being tested for HIV, I was not given any other information. I did not question anything at the time.

20. I was vaccinated against Hepatitis A and B.

21. I do not know if I was treated or tested for the purpose of research.

Section 5. Impact of the Infection

22. Before I was diagnosed with Hep C, I started to feel fatigue. I never knew that this was attributable to the infection at the time, until I was diagnosed. My girlfriend then, whom I had been with for ten years, would get extremely frustrated with me. Whilst she wanted to go out and socialise in evenings with friends, I wanted to stay indoors and relax. Most evenings I was only able to sleep. I was unable to do simple everyday things a young 20 year old would do. Even visiting my girlfriend's parents in the next village was difficult in the evenings. Neither of us knew about fatigue or the reasons for it. Even our sex life was impacted and the strain on the relationship became too much as I was constantly physically debilitated. As a result our relationship ended.

23. Since the mid 1990s, I have battled with fatigue, tiredness and brain fog, and I have seen the doctors on countless occasions about it. In the end I was told that nothing could be done about it, so I had to manage it by myself. If there was something that I needed to do, but I knew that it would be tiring, I would think ahead about how best to approach it to minimise the impact on me. I had to prioritise my life, the most important being work as it brings in the income, then family, and then my social life. As I progress down that order, if I get tired, I will have to put off the latter activities. Other than fatigue, I have also suffered from severe mood swings and hair trigger anger. I have to work very hard on a daily basis at stabilising my emotions and my wife and step-

daughter often take the brunt when I'm unable to control outbursts – usually when I'm particularly fatigued. This is deeply distressing for me.

24. As previously stated I was told in 1996 that I had Hep C, no further investigation or biopsy occurred until 1999. Even after that, nothing happened until 2004 when I was offered Ribavirin and Interferon treatment and I was referred to the Hepatology Department. The course of the treatment was for 6 months. I was not offered any other treatment and I was told that the above treatment was the only one available to me. The treatment was successful and I was told that my viral load was undetectable, although the fatigue has never disappeared.

25. In my medical records there is correspondence stating that they had lost contact with me. However, I can confirm that I had still been attending the hospital for annual reviews and obtaining treatment in relation to the Haemophilia, so I do not understand how they came to the conclusion that I had gone off the radar. I was cautious about taking time off work to have biopsies. However, I had always taken medical advice and kept in regular contact with the hospital.

26. Before I started the treatment, I was so laid back, people used to call me horizontal. When I was put on the treatment, I started experiencing personality changing mood swings. I changed into an aggressive, high tempered and blunt man. To this date my mother is cautious about calling me because of my mood swings. It was horrible to live with the mood swings as in the heat of the moment, I got so frustrated, but after having calmed down, I would wonder where that frustration had come from. This kicked in almost instantly after starting the treatment. The doctors said that it is a known side effect and nothing could be done about it. My GP gave me anti-depressants and I tried taking them, but they make no difference. Whenever I go to the GP regarding my mood, she tells me to take the anti-depressants for longer, and I have to repeat that they do not work.

27. Before I started the treatment, I was called into the hospital at 4:30pm to be taught how to administer the injections myself. I was completely unprepared.

The first shock of treatment was appalling. It was a tough treatment. I felt so unwell and sick. I had a fever and was sweating profusely. I lived on my own at the time so there was nothing in the fridge for me to eat. I was unable to live a normal day-to-day life. The symptoms would start wearing off at the end of the week and I would start to recover but then I was due another injection and the symptoms repeated itself. I believe the mood swings had a name: Riba Rage. At that time it was completely unknown to me. I was given a leaflet with all potential side effects and I had them all except for hair loss.

28. Whilst I was on treatment, I was in a very well paid job, but to get to work I had to endure a one hour commute. I survived and was determined not to take time off, but I ran myself into the ground. I therefore had to give up that job. I could not manage driving on the motorway and if I did, I would have a full on anxiety panic attack. I couldn't get myself to work and it cost me my job. I recall when I was on conference calls I used to randomly swear at them. It horrifies me to think that as a professional man, I did something so uncouth. I don't think that the rage has left me entirely. My level of frustration and anger is spontaneous and uncontrollable. If I am not careful, especially when I am tired, my response blows up and takes me by surprise. Those around me have no idea it's coming.

29. I had a huge problem with concentration and it has affected my work. The work that I do is very technical and complex and I continue to struggle with it now. It is almost like a mental deflation. I find it difficult to muster energy. Everything I do is challenging. It is so difficult to verbalise.

30. I am now open about my infected status and if someone has a problem with it there is nothing I can do about it. I cannot change the way others perceive me. At work I have been honest and I have told some of my colleagues. On more than one occasion, two of my ex-employers sent me to occupational health to ensure I am safe to work in their company. Although I try not to let it affect me, the stigma is always there.

31. As previously stated I had to give up a highly paid job because of the treatment. I did return to a paid job after the treatment but the salary was

significantly affected. I am now currently freelancing. I have been forced to freelance because I feel that I am in control and able to manage my ongoing symptoms, which I attribute to the treatment.

32. I work in IT and technology is always changing. Accreditations expire every two years. I therefore have to study new courses and pass the exams in order to continue with my job. Studying and retaining new knowledge is becoming increasingly difficult as it requires time outside of usual working hours including the weekends. I do not have the energy to keep up. This is affecting my ability to attract freelance work and the rate I can charge as a lot of my accreditations have expired because I cannot manage the evening time study required to retain all of them. I am already looking to the future knowing I cannot continue in my chosen career and considering what I will be able to do in the near-mid future to maintain an income.

33. As previously stated I am unable to hold down a full-time job. I take on contracts and when the contract terminates, I take time off to recover and study before I sign a new contract. Before I was diagnosed, I never had this problem.

34. Before the treatment I was on an annual salary of £45,000 in addition I had a decent company car. As a result of losing my job, I lost a huge amount of income. When I returned to work I was receiving a salary of £28,000 without the benefit of a company car. This was a significant decrease in salary. Even the salary I obtain through freelancing does not match the £45,000 that I received before the I started the treatment. If I was able to work year round, instead of relying on contracts, I would certainly be in a better financial situation now. I had to take time off in between various contracts to recover. I would much rather be employed. Prospects of career progression are higher for employees and I would be entitled to a pension. The hassle of doing my own taxes and responsibility of running a Limited company causes a lot of inconvenience, hassle and stress.

35. My step-daughter took the brunt of my mood swings. She is now nineteen. My ability to lose my temper quickly and spontaneously was not an ideal

environment for her to grow up in. I am thankful that she is very forgiving and loving and we are very close, but she grew up walking on egg shells around me, not knowing what would cause the next big blow up. My wife, whom I married in 2011, is also extremely supportive and understanding. Our relationship has been impacted as I lack the energy to go out or do things that normal married couples do.

36. I cannot stress strongly enough how much impact my health and mental state impacts my immediate family. I consider myself to be extremely fortunate to have such a supportive family but I also know from previous experience that this isn't something that can be taken for granted and it really is a relationship killer. Without supportive family, life is significantly harder to live and cope with symptoms

Section 6. Treatment/care/support

37. There had been a delay of many years in relation to what treatment was available and I wasn't given the opportunity to be put forward for any trials. I do not believe that the doctors were very helpful in giving advice about my symptoms. As previously stated, I am told that nothing could be done in relation to the fatigue and mood swings that I was suffering. Even within the previous 12 months I am told by my GP that nothing can be done to assist with the fatigue, mood swings or my concentration. I was given general anti-depressant medication but it did not work.

Section 7. Financial Assistance

38. In 2004, I received a lump sum of £20,000 from the Skipton Fund. For one year I was unable to work following Hepatitis C treatment. The treatment was so aggressive and unpleasant it took almost a year to recover from it sufficiently to return to work. I survived solely on that money. I believe everybody who had been infected with Hep C through contaminated FVIII concentrate was entitled to this payment.

39. I am also in receipt of a monthly EIBSS payment. When the Special Category Mechanism (SCM) became available, I received £1,500 per month which was backdated to October 2017 and approved in February 2018.

40. The only thing I applied for is SCM and for that I had to complete a form and send it to the Haemophilia Centre to complete. I was registered at the Oxford Haemophilia Centre by then, but my medical records were retained at BRH whom I had to contact. By way of writing a personal statement, I had to produce evidence that my symptoms were attributed to Hep C, but that was a hurdle to overcome. The EIBSS had a list of eligible medical conditions, the majority of which I had never heard of. In the end it was down to the consultant at BRH to acknowledge that my symptoms were attributable to Hep C.

41. With the manner in which I work now, there is an element of stress in knowing that when my contract comes to an end, I will need time off work therefore there will be an immediate financial impact. Without that time off to recover from my fatigue, I cannot work.

Section 8. Other Issues

42. For the longest time I believed what they told me – that they had no idea the risk of infection through FVIII existed. This is simply not true at all. I continue to struggle with the residue symptoms of Hep C and I know, regardless of the Inquiry's result, I still have to live with those symptoms.

Anonymity, disclosure and redaction

43. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

44. I do not want to give oral evidence.

Statement of Truth

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

Signed.....GRO-C............

Dated 1\5\2019