Witness Name: Terence Workman
Statement No: WITN1617001
Exhibits: WITN1617002
Dated: 27th January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF TERENCE WORKMAN

I, Terence Workman will say as follows:-

Section 1. Introduction

1. My name is Terence Workman. My date of birth is the GRO-C 1954 and I am 62 years old. I live at GRO-C with my wife Sonia, we married in 1995 and unfortunately we do not have any children. In 2015 I took early retirement on the grounds of my ill health.

2. This witness statement has been prepared without the benefit of access to my full medical records. There is now produced and shown to me marked Exhibit 'WITN1617002' my records received from the National Haemophilia Database.

Section 2. How infected

3. I was diagnosed at about the age of 1 with severe Haemophilia A, I was initially treated with Cryoprecipitate (Cryo) from 1969 to 1977 then from 1977 to the present day with Factor VIII.

4. I recall being told later in my treatment that I could no longer be treated with Cryo because it was meant to be given to younger children; therefore it was not suitable for me anymore.

5. I believe that from 1977 to 1998 I was treated with Factor VIII produced by BPL, Factorate, Oxford FVIII, FVIII 8Y (BPL) and Replenate (BPL); from 1998 to 2006 I was treated with Factor VIII produced by Profilate, Fanhdi, Alphanate, Replenate (BPL) and Helixate; and from 2007 to the present day I received Factor VIII produced by Advate and Refacto.

6. I received treatment from the Birmingham Children's Hospital and was under the care of Dr J. Stuart and Dr Mann. Later I was treated at the Queen Elizabeth Hospital in Birmingham and was under the care of Dr J. Stuart (later to become Professor J. Stuart), Dr B. J. Broughton, Dr I. M. Franklin, Dr. M. Williams, Dr. F. G. H. Hill and Dr J. Wilde.

7. I do not recall at any time being informed of any risks of taking Factor VIII.

8. As the result of receiving Factor VIII I have been infected with Hepatitis C (HCV).

9. I recall receiving a short letter in a brown envelope from Queen Elizabeth Hospital in the early to mid 1980's informing me that I had been infected with Non A, Non B Hepatitis which I am now aware refers to HCV. I cannot find this letter. I was not concerned about the diagnosis as the letter indicated that there was nothing to worry about and no further treatment or investigations were required.

10. Later in the mid to late 1980's I received a letter from Queen Elizabeth Hospital stating that I had been infected with HCV. The letter enclosed a general booklet about the infection. The letter implied that the infection did not carry too much risk but that there was a small risk that I could develop cancer as a result of the infection which I was slightly concerned about. But I was not given any details about how HCV could be transmitted. I no longer have this letter.

11. It was not until March 1994 that I attended a joint appointment with my Haematologist and the Liver specialist and was told the seriousness of this virus. Up until then I was not too concerned. I was told I required a liver biopsy and quoting the liver specialist I was told, "You could die from something else during the next 15 years". I came out of that appointment in a daze and confused. I went in thinking I was fine and came out thinking, have I just been told I may be dead in the next 15 years because of this virus. I was getting married the following year and expecting to be able to start a family.

12. I was still not told how the infection was spread or cross contaminated. I recall specifically asking my doctor, as to whether I should take any precautions with my partner; however, I was informed that there is no such need.

13. I have found out about the risks of infecting others by myself, from my own research. I was never told by any of the doctors about the potential risks to my wife.

14. Looking back now I was not given adequate information to help me understand and manage the infection. I had six-monthly check ups at the hospital when I was monitored and my liver function tested. The infection was discussed there but the doctors did not place too much concern on it.

15. I do consider that I should have been given information about the infection earlier but the doctors did not know too much about it. I certainly believe that the seriousness of my illness should be emphasised more from the beginning.

Section 3. Other Infections

16. As far as I am aware I have not been infected with any other infections. However, in about 1987, I was told at some point that I might have been infected with Human Immunodeficiency Virus (HIV) and a sample of my blood was taken and

sent to America to be tested. I do not have HIV but I was told I had been exposed to it. It was a very traumatic time waiting for the result of the blood test.

Section 4. Consent

17. I have no proof that I have been treated or tested without my knowledge or consent. Although I find it hard to believe that I was not being tested for HIV or other viruses without my knowledge.

Section 5. Impact

18. The mental impact of finally being told in March 1994 of the implications of having HCV was very severe and devastating. I was getting married the following year in 1995 and was expecting to start a family.

19. As a result of HCV, I have experienced extreme tiredness and exhaustion constantly. Aches and pains that cannot be explained in my muscles and joints. I have memory problems and brain fog, as well as lack of concentration, loss of appetite and weight loss.

20. I first started treatment for HCV in 2012 which included the Interferon treatment. A few weeks into the treatment I suffered from fatigue, tiredness and nausea as a result of the drug combination. Following this I also suffered from severe mental problems associated with the Interferon treatment. My symptoms included severe anxiety and panic attacks, I was just walking around, I could not sit down and settle into anything.

21. The mental problems were so bad that after eight weeks of starting the treatment I was actually crying on the telephone to the Haemophilia Sister at the Queen Elizabeth Hospital begging to be taken off the treatment. This was agreed and an emergency appointment was made for me to attend my GP's surgery when I was given an urgent prescription for Diazapan. I was treated with Diazapan for three

or four months. I still feel to this day I never recovered from this treatment and still get panic attacks and anxiety.

22. In 2015 I received my second course of treatment which was non-Interferon based. I had been on the waiting list for treatment for four years. I have discussed my options with the doctors and we decided to wait for better drugs to be developed.

23. I recall being told at the time that I needed to remain on the waiting list as no patients could be prioritised, regardless of the way in which the virus was contracted.

24. Fortunately, I cleared the virus in 2016 and I no longer need to receive any treatment for HCV or take any medication.

25. Also the result of a fibroscan of my liver is ok; the liver function test is also satisfactory but a biopsy of my liver shows it to be enlarged.

26. My wife and I married in 1995 and planned to have children of our own. However, we both felt that as I had been given a poor prognosis the year before that I may not be around to provide for my wife and family. Also the decision was made because I could not get any life insurance due to my diagnosis. There was also the issue that I may pass on the virus to my wife or unborn child, so taking everything into consideration; very regrettably, we decided not to have children.

27. I also felt unable to tell anyone else, apart from my wife, that I had contracted HCV because I felt people may think I could pass the virus onto them. In particular I did not tell my mother when she was alive as I did not want her to worry.

28. One of the biggest impacts HCV has had on my life was the decision I took in 2015 when I was 58 to take early retirement from work due to my ill health. I had previously enjoyed a very successful and enjoyable twenty-five year career

working for the Department of Work and Pensions (DWP) in Wednesbury and West Bromwich. I felt I could no longer sustain my level of service due to my ongoing mental and physical problems caused by my infection. This has resulted in severe financial and social problems for both my wife and I.

29. My wife works four days per week and has a very understanding employer as she has had to take time off work to care for me. My infection has also caused her great stress and anxiety as she does not know what is going to happen to me.

30. All this has also come at a great cost to my wife who has been unable to have children, something she always wanted, and the time she has had to take from work to care for me and the financial strains this has now put us under.

31. Despite all our difficulties we still socialise and live life best as best as we can, we have tried to carry on as normal as we could.

32. I have to receive dental treatment at the Queen Elizabeth Hospital.

Section 6. Treatment/Care/Support

33. I have not faced difficulties or obstacles in obtaining treatment as a result of being infected with HCV.

34. I have not been offered any counselling or physiological support as a result of being infected with HCV. I feel that this would have been helpful at the time.

Section 7. Financial Assistance

35. I have received some financial assistance from the Trusts and Funds. In 2005 I received a letter from the Skipton Fund stating that I might be entitled to funding. As a result I received the one off £20,000 payment from the Skipton Fund.

36. Following the receipt of the award, I have also received a payment for the help to purchase a bed settee for when I am unable to get upstairs to my bedroom, and a payment to assist in the purchase of an electric multi position bed for the bedroom to help relieve the pain from my joints.

37. At first I was told that the NHS should provide multi-position bed until I pointed out to them that the NHS would never provide such things. I backed this up with a letter from the Haemophilia Sister at the Queen Elizabeth Hospital.

38. I am also in receipt of the ongoing payments from the EIBBS. Initially I received £250 per month then about six months ago due to my condition, I applied for the Special Category Mechanism payment which increased my monthly payment to £1,500. My consultant assisted me in filling in the forms and fortunately the application was successful. However, I would like to add that none of these payments make up for having to retire early from my employment with the DWP.

39. The forms are themselves obstacles, they are very long and detailed and as a result I gave up applying for funding. Also when I was working my wife's income was taken into account in any decision to award financial assistance to me which I felt was unfair.

40. I have had forms about claiming for other items in the past but in my opinion they make you feel that you are asking for charity which is very against my nature.

41. I have not had any dealings with the Funds in recent years so cannot comment on the current process for applying for funding.

Anonymity, disclosure and redaction

42. 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.

43. I am willing to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

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

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

Terence Workman

Dated; 27th January 2019