Witness Name: GARY JAMES WEBSTER
Statement No: WITN1723001
Exhibits: WITN1723002-5
Dated: DECEMBER 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GARY JAMES WEBSTER

I, Gary James Webster will say as follows:-

Section 1. Introduction

1. My name is Gary James Webster. My date of birth is GRO-C 1965. I live at GRO-C Hampshire GRO-C with my partner, Leza. I have one daughter, Amy, aged 18 and a grandson, GRO-C aged 3. I retired from work on medical grounds in 2011.

2. 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

3. I have severe haemophilia A. I was diagnosed at aged 6 months because of spontaneous bleeds. I am prone to spontaneous, unpredictable bleeds into my

joints. Due to multiple joint bleeds in the past, I have chronic arthropathy and have had major surgery on my knees, ankle and elbow. I am disabled and in receipt of DLA and ESA benefits.

4. In my early years as a child I was treated with plasma and cryopreciptate twice a week and required admission to Basingstoke Hospital on numerous occasions.

5. I transferred to Lord Mayor Treloar College Haemophilia Centre, Holybourne, Alton, Hampshire, Alton, Hampshire in the mid 1970s when I started attending school there at 10 years of age. I boarded there until I was 18 alongside a large cohort of fellow haemophilia patients. Initially I was under the care of Dr Kirk, Dr McCarthy and Dr Reynsford and then Dr Wassef and Dr Anthony Aromstan. Dr Wassef retired in 1990. Whilst at Treloar College, I was given Factor VIII (FVIII).

6. I am co-infected with Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV). I was told that I had contracted HIV in the early part of 1983. I do not know when I first tested positive.

7. I was told that I was diagnosed with HCV in 1985. It was previously called non-A, non-B Hepatatis. I am not sure when I first tested positive.

8. I have requested copies of my medical notes and records from (a) my GP; (b) Basingstoke Hospital and (c) the Treloar Haemophilia Centre. The medical notes and records I have received from these three sources are deficient as the information pertaining to the diagnosis of my HIV and HCV including the information detailing when I was tested for the infections is missing. I was formerly told by the Treloar Haemophilia Centre that my medical notes and records had been destroyed. I received a telephone call from the Centre on 25th October 2018 advising me that my notes spanning the relevant time (1975 to 1983) period has been found by The Treloar Centre at the back of a cupboard. Aside from some treatment record documentation from that time referred to at **Exhibit WITN1723002** the relevant information is missing.

9. My medical notes and records are non-specific in relation to my diagnoses. I refer to **EXHIBIT WITN1723003** being a letter from the Hamemophilia Cetnre to my GP dated 20th September 2004 stating that I "was diagnosed with HIV in 1990 if not earlier". I believe it to be clear that my medical records had been tampered with/removed at that time.

Advice Given regarding the Risk of Infected Blood Products

10. I was given no advice in relation to the risks associated with infected products. My parents were also not given any advice.

Discovery of Infection

11. In what I believe to be the early part of 1983, I was called into the school office with a class mate, GRO-A Dr Wassef and Dr Aromstan told GRO-A and I together that we had HIV. It was all very matter of fact. From what I can remember Dr Wassef said "You have HIV. We are not sure of the implications but what we can say is that it is incurable and we cannot guarantee that you will be alive in 6 to 12 months". GRO-A and I just looked at each other in disbelief and then we laughed (through shock). I was just 17 years old when I was informed of the diagnosis. I had not yet had my 18th birthday and I was due to leave the school that summer.

12. No information was given to us to help us manage the condition and no treatment was offered. There was no treatment at that time. I later learned that 88 fellow haemophiliacs at the school had contracted HIV through blood products whilst at the school. Some of us (like GRO-A and I) were called in to be told in pairs and many of the younger pupils, as I recall, were called in in groups (with the school nurse also present). I had no treatment for HIV until the late 1980s. The only thing they started doing differently straight away was to give us heat treated Factor VIII.

13. I believe that the information about my diagnosis should have been provided earlier and that my parents should have been informed first. It was left to *me* to tell my parents which I did at my next home visit. I went home to stay with my parents and younger brother, Paul, every third weekend of the month. I remember telling my parents in our front room. They were upset and shocked.

14. I do not believe that I was given any information about the risk of infection to others. I had seen the TV campaign with the tombstone and knew that HIV was a deadly disease mainly passed on through sex.

15. In 1985 I learned that I had HCV. By that time I was working for Moss Bros as a qualified tailor. I was still being treated at Treloars. I returned there for blood tests and monitoring. Many of my fellow pupils had become ill with HIV and were dying. I was a non-progresser. My father had heard something about haemophiliacs contracting (non-A, non-B) hepatitis and phoned Treloars to ask. They refused to tell him whether I had it because I was (now) over the age of 18 and they said that they would only talk to me and not him. I went up to the College and was told by Dr Wassef that I had it. I do not believe I would have been told had it not been for my father calling.

16. I do not recall being given much information about HCV. I do not think they knew much about the condition. I did not know what to do about the diagnosis. I was under the impression HIV was worse. I recall thinking it doesn't make any difference as HIV/AIDS would kill me first. I had no information about HCV for years. They just did blood tests every few months. I refer to **EXHIBIT WITN1723004** being a document which is I believe indicative that I was tested for some form of hepatitis as long ago as 23rd January 1976.

Section 3. Other Infections

17. I have been informed that I am at risk of CJD.

Section 4. Consent

18. I was tested for HIV and then HCV without my consent and without having been given adequate information. I was not told nor was I aware of the tests. They took blood for testing regularly but I believed it was for routine tests and was not told otherwise.

19. I believe that I was treated with FVIII for research purposes. We, at Treloars, were given FVIII on a prophylaxis basis regardless of whether our haemophilia was mild or severe every other day. I actually only needed treating for a bleed once or twice a month. It felt like we were being used as guinea pigs. It looks to me now that they were just filling us with FVIII to see what happened.

Section 5. Impact

Physical effects

20. My immune system is so low that I catch just about any infection I come into contact with. A simple cold invariably becomes flu and turns into a chest infection. I am constantly fatigued. I have had warts, countless chest infections and bouts of pneumonia and many sickness bugs.

21. In or around 2009, because of the amount of infections I was getting, I was treated on highly active anti-retroviral (HAART) medications for my HIV and also prescribed methadone to reduce my opiate intake given for pain due to multiple haemophilic arthropathy. During treatment I had multiple problems with abdominal pain and recurring diarrhoea.

22. HCV has destroyed my liver and I have been in terrible pain. I commenced clearing treatment for HCV with a combination of pegylated Interferon and Ribaviran for six months in 2009/10 but this was unsuccessful. The treatment

was so awful that I really thought the drugs would kill me. I experienced chronic vomiting and stomach troubles and had a biopsy. I ended up in hospital for a month with pneumonia. I started treatment again in the summer of 2018 and am waiting to see if it has been successful. Hopefully there will be no further damage to my liver.

23. I first had fibrosis on the liver, which developed into cirrhosis in March 2011. I was diagnosed with Stage 2 liver cancer 3 or 3 years ago. The latest test result indicates that my liver cancer may be in remission.

Mental effects and Stigma

24. Being diagnosed in 1983 at age 17 was a very scary time to receive an HIV diagnosis. The worst thing was the stigma. I lost a lot of friends, girlfriends and potential girlfriends. If you had HIV you were bundled into a "gay club". Everyone thought you were gay and that HIV was contagious. I always tried to go out socialise. I ignore it now but people back away from you if they know you are HIV positive.

25. The health professionals are often the worse. I could not get a dentist initially. As soon as I said I had HIV or HCV they didn't want to know. So I have to stick to using the dentist at the Haemophilia Centre. I have not tried for a few years so it might be different now. I have been segregated in hospitals with a big sign on my door and everyone entering being barriered up.

26. In or around 2014 my elbow operation was cancelled because they realised I was a CJD risk at the eleventh hour. I had had my pre-med and was gowned and ready to be taken to theatre when I was told that they needed to buy a drill that could be disposed of after the operation.

27. Being infected with HIV and HCV through no fault of my own has ruined my life. I can handle haemophilia but these infections are killers. The vast majority of my

school friends have died. There are only 17 of us still alive out of 89 infected. My close relationships have been irreparably damaged to include the breakdown of my marriage in the late 90s and the breakdown of my relationship with Amy's mother, Sadie, shortly after she was born. Throughout my 20s and 30s it was really tough. I was on a mission to destroy myself and basically lost the plot. I went off the rails and didn't care about myself. On one occasion I drove a car through a brick wall and broke my ankle in the process.

28. GRO-C and the worry started as soon as Sadie became pregnant. The relief when Amy was born free of infection was massive. After she was born, I worked and tried not to let HCV and HIV bother me for sake.

29. Up until the HCV clearing treatment commenced in 2009 I held down a responsible position of authority with the Red Cross involving the organisation of around 5,000 volunteers for them and necessitating daily travel covering Hampshire, Surrey and Isle of Wight. I was earning £30,000 to £40,000 per annum. I am no longer able physically and mentally to do that. I am tired and depressed and have lost interest in life.

30. My parents and my daughter Amy have all struggled emotionally. Amy often says she doesn't know if she is going to wake up one morning to learn that her dad is dead.

Section 6. Treatment/Care/Support

31. No counselling or psychological support has been made available to me.

Section 7. Financial Assistance

32. I received two lump sum payments from the MacFarlane Trust. The first lump sum was for £20,000, the second for what I believe might have been as much as

£50,000. I also applied for two grants, one for double glazing and the other for a replacement conservatory. The applications were time consuming but the grants have been helpful.

33. I also receive regular monthly payments. Initially these were through MacFarlane and Skipton (Stage 1 and 2). They are now paid by EIBSS. Without the monthly payments I would be unable to make my monthly mortgage repayments and pay my bills. I am no longer able to work and rely on these payments together with DLA and ESA benefits.

34. Last year I needed to renew/renegotiate my mortgage as I ordinarily try to secure a low fixed rate affordable to me in terms of repayment. Now that I am unable to work it has become problematic for me to provide evidence of guaranteed income as EIBSS will not commit to stating that the funding will be available to me for life (like a pension). It is not easy to get through to and/or speak to anyone helpful at EIBSS. EIBSS are unwilling to provide me with a letter to assist me and would only say that the Government are *currently* making payments.

35. I am unable to get life assurance.

Section 8. Other Issues

35 I refer to **Exhibit WITN1723005** being a copy of the article published in the Sun newspaper on 24th July 2017. There are no other issues.

Anonymity, disclosure and redaction

36 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. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 20|12|2018