Witness Name: MARCUS DAVID NIGHTINGALE
Statement No: WITN1434001
Exhibits: WITN1434002
Dated: NOVEMBER 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARCUS DAVID NIGHTINGALE

I, MARCUS DAVID NIGHTINGALE will say as follows:-

Section 1. Introduction

1. My name is Marcus David Nightingale. I was born on GRO-C 1967. I live at GRO-C with my wife, Sarah. We have a daughter, Jade, born on GRO-C 1992. I am by occupation a retired car-sprayer. I was made redundant 15 years ago. I was in effect retired on medical grounds as my joints are damaged to the extent that I am no longer able to work.

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 moderate Haemophilia B (otherwise known as Christmas disease) with less than 5% clotting factor.

4. I was diagnosed as having Haemophilia in 1974 when I was 7 years old. I bit my tongue, it needed stitches and would not stop bleeding. My mother was identified as a carrier.

5. I was initially treated at the Manchester Children's Hospital, Haemophilia Department under the care of Dr Evans. I was then treated at the Lancaster Royal Infirmary, Haemophilia Centre under the care of Dr GRO-D and then Dr Keating. I am currently treated at the Manchester Royal Infirmary under the care of Dr Hay.

6. I was treated with Factor IX (FIX) blood products on numerous occasions as I had quite a few injuries and bleeds. I refer to **Exhibit WITN1434002** being my UKHCDO Patient Treatment Record. I believe this document to be wrong/deficient. I was treated with FIX prior to the date of 1992. I was treated with FIX by my GP, Dr Lynch at his surgery and at his home. I remember going to his home as a young child. He kept the blood products in his fridge. I was also treated with FIX throughout the 1970s and 1980s at the Moor Hospital in Lancashire and, on one occasion, the Beaumont Hospital, Morecambe.

7. I know that my Mum and Dad were not given advice about the risks of being infected. I was never made aware of any risk or given any advice about the risk of infection from FIX treatment.

8. I do not remember exactly when I was informed that I had contracted the Hepatitis C Virus (HCV) but I believe it to have been in or around 1994. I have had ankle problems (bleeds and swelling) since my late teens to include a cyst

that had formed on my left ankle. Dr GRO-D at the Lancaster Royal Infirmary took xrays. He called me in for a follow-up appointment and told me that I had arthritis in my ankles and that they needed to be fused. On top of that piece of news, he went on to inform me that I had Hepatitis C. He knew because he had tested me for it. I was shocked because I did not even know I was being tested for any infections and I had not ever heard of HCV.

9. Dr GRO-D told me that HCV would affect my liver and it could shorten my life. That was all the information he provided me with. He attempted to negate the impact of the news by saying "the good news is that you don't have HIV". He did not give me any information on how to manage the infection, or how to understand and treat it. He did not tell me anything about the risk of infecting others. I went home and told Sarah and we just carried on with life because neither of us knew what it was.

10. Sarah and I were given more information at an appointment at the Oxford Haemophilia Centre some months later. We thought we had been sent there about my ankles but they were more interested in my infection. I was told there that batches of blood products were infected with multiple viruses. They advised Sarah to have a blood test to see whether she too was infected. Our primary concern was our daughter Jade. We were so worried about her GRO-C GRO-C. We were given a leaflet about the risks of having more children. GRO-C GRO-C This was a worrying time.

Section 3. Other Infections

11. I have been vaccinated against the Hepatitis B Virus (HBV) and I keep on top of these immunisations.

12. I was informed that I might have the Hepatitis D, E, F and G viruses. However, there are apparently no tests available for these infections. I would not be surprised if something else is discovered in my blood over the next ten or twenty years.

13. I also received a letter saying that I am at risk for vCJD. It stated that there is no test or cure for this infection. I feel that this is just another ticking time bomb that could go off at any point. Unfortunately, the risk of being exposed to this virus means that I have faced delays in getting certain medical treatment and operations. In particular, getting an appointment for any dental work seems to take ages. I have been told that after an operation the staff must destroy everything, as I believe vCJD to derive from a prion rather than being a virus, so they cannot sterilise against it.

Section 4. Consent

14. I know that I was tested for a number of infections without my knowledge and consent. I had regular blood tests every six to twelve months in relation to my haemophilia, but I was not told that I was being tested for HIV or HCV. The first time I knew about this was the day when Dr GRO-D told me I had tested positive for HCV and negative for HIV.

15. I have been tested for research but with my consent. Dr GRO-D asked whether I would agree to a professor (I do not recall his name) taking blood for research purposes (to help others with haemophilia). I agreed to this but I now question whether I was being tested for other forms of infection.

Section 5. Impact of the Infection

16. Sarah and I would have had more children but acted upon the advice not to do so because of the risk of passing on HCV.

17. I am now considered to be clear of HCV, but I still suffer from fatigue, brain fog and difficulty remembering things. I have a fatty/damaged liver and undergo liver function tests and ultrasound scans every 12 months. I have to travel to Manchester. I have been told that my liver is not getting any worse.

18. I have a lot of damage to my joints and have had a number of operations to my ankles, hip, shoulder and wrist. I have had both of my ankles fused, a hip replacement and an operation on my shoulder. I believe the HCV to have contributed to the damage to my joints, particularly my ankle. HCV can cause cysts in joints. A cyst had formed in my left ankle joint in or around 1994 when I was told I had HCV. Some of my bleeds were untreated. I put up with bleeds to joints rather than risk having more infected blood. I had to retire around 15 years ago because of my health issues.

19. I have had to endure three attempts at clearing the HCV infection. The first attempt was in or around 1996 and involved interferon injections three times a week for six months. Each injection felt like a massive dose of flu to the extent that I felt lousy and I struggled to get out of bed. The HCV initially looked to have been in remission but then returned.

20. With the second attempt a couple of years later, this time over a 12 month period, I suffered from nausea, night sweats, vomiting, loss of appetite and lost weight. The treatment also affected my mood. I was determined to carry on working and did as much as possible for my daughter, Jade in taking her to school and the like. I was constantly exhausted. It was a difficult time. Sarah and I argued a lot. There was tension between us. However, I did not want to stop the treatment. I had an abscess and infections in my gums and had to have the three teeth taken out. I was informed that this was because my immune system had dropped from being on treatment for such a long period of time.

21. I was determined to clear the virus but the treatment again proved unsuccessful. Although I have a positive outlook on things and consider myself to be mentally quite tough, this was really disappointing and I know that it made Sarah worry.

22. The third course of treatment in or around 2001 and involved an interferon injection and some tablets to include ribavirin twice a day over a period of 18 months. The HCV infection I had was Genotype A, the most difficult to clear. Fortunately, the treatment cleared the virus notwithstanding the fact that Dr Keating at Lancashire sought to halt the treatment after the third month.

23. Being unable to work for 15 years has had a significant financial impact on my family. My wife had to return to work on a full time basis to help finance our outgoings and to pay for activities our daughter would have been unable to do otherwise, for example dancing and swimming lessons.

24. I have never told my employer or work colleagues that I have haemophilia let alone HCV. Out of ignorance people associate haemophilia with HIV and make the assumption that anyone with HCV is likely to be a drug abuser and sharing needles. We only told very close friends and family members about my health issues.

Section 6. Treatment/care/support

25. I was informed by Dr Keating at the Lancashire Royal Infirmary that the clearing treatment I started in 2001 was expensive and that he would be stopping it after three months. I understand he told other patients that their treatment would also be cut short. Fortunately for me Dr Hay intervened and the Manchester Royal Infirmary took over the funding for the treatment. Dr Hay argued that three months was not enough time for the virus to clear and that as a haemophiliac I had contracted HCV through no fault of my own. He ensured that I had an 18

month course. Without his intervention I very much doubt that I would have successfully cleared the virus.

26. The funding for the treatment was clearly an issue and my treatment was placed at risk as a result. During the course of that first three months Dr Keating told me to go to my GP for the blood tests required to monitor my clearing treatment. My GP was very clear about the fact that this should not have been the case and that the tests should have been the hospital's responsibility.

27. I have not ever been offered counselling. I do not know whether I would have accepted an offer of counselling, but I think Sarah may have found it useful as she has been through a great deal of anxiety and stress.

Section 7. Financial Assistance

28. I received the Stage 1 £20,000 ex gratia payment from the Skipton Fund. I used the money to pay off our mortgage so that our home is secure.

29. It is hard work trying to get financial assistance for anything. You are required to provide them with two estimates for the work and when they write back to decline your application it feels like a waste of time. You really have no idea when making an application whether it will be successful or not.

30. I applied and obtained a grant from the Caxton Fund to provide us with payments to finance the first term of Jade's dance college when she left school. We had not applied for anything before that.

31. We have since applied for grants for car maintenance. The process is laborious and involved obtaining estimates. The decision making seems somewhat random in terms of outcome. I applied for a grant to replace our car radiator and this was turned down.

32. I am in receipt of Disability Living Allowance. I receive approximately £3,500 annually divided into regular monthly payments from EIBSS formerly the Caxton Fund. I have had a more positive experience with EIBSS.

Section 8. Other Issues

33. We have not travelled abroad because of the difficulty getting travel insurance. I am unable to obtain life insurance. If you mention HCV to an insurance company you are instantly blacklisted, even if you have cleared the infection. I had to undertake an independent HIV test before I obtained a mortgage (because I am a haemophiliac).

Anonymity, disclosure and redaction

34. 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 do not wish 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 29/11/18

Medical Summary

(This summary is not intended to e exhaustive but sets out key points in the records relevant to the statement)

This witness statement has been prepared without the benefit of access to my full medical records. I have my UKHCDO patient record and nothing more.