

Witness Name: M J Merry
Statement No: WITN1389001
Exhibits: WITN1389002-6
Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MATTHEW JAMES MERRY

I, Matthew James Merry, will say as follows: -

Section 1. Introduction

1. My name is Matthew Merry. My date of birth is GRO-C 1974. I am married and live with my wife at GRO-C I have two sons aged 8 years and 5 years.
2. I believe I was infected with HIV and Hepatitis C between 1982 and 1985 as a result of being treated with Factor VIII products that were contaminated. My first recorded HIV+ test was on the 14th May 1985 at Coventry and Warwickshire Hospital. I have also been notified by the Royal Free Hospital in London in 2004 that I have received blood products derived from a donor that was later diagnosed as having vCJD.
3. **This witness statement has been prepared without the benefit of access to my full medical records.**

4. As I was very young when I was being treated, I have spoken with my parents to obtain information. They are currently in their early 70s and both they and my brother also intend to give statements to the Inquiry.

Section 2. How infected

Family background

5. Haemophilia runs in the family on my mother's side. My mother is a carrier. I was diagnosed with severe Haemophilia A at birth. I have one brother, Simon, who is also a severe Haemophiliac GRO-C
6. Simon was also treated with FVIII blood products and was infected after being treated with FVIII products just like me. FVIII products were given as a matter of course. The doctors gave me no other treatment option and no advice.
7. FVIII concentrate was either the UK version given to the NHS to use on patients or was produced commercially such as that produced by Armour imported from the USA, both of which were provided to us.

Coventry and Warwickshire Hospital, (CWH) (1974 – 1994).

8. When I was about 4 years old, I started getting spontaneous bleeds. They were mostly in my left leg but I occasionally got these from knocks which could be anywhere on my body. Most of these bleeds were in my left ankle and other joints
9. From 1978 to 1982, the doctors at CWH treated me at the hospital if I required injections. If these bleeds were out of regular hours, my parents had to take me to Walsgrave Hospital (WH) which was 13 miles away. We often had to wait a long time for the Haemophilia registrar on-call to come and see me and then go and mix-up my Factor VIII injection. I believe this delay in

treatment, at such a young age, contributed to the poor condition of my left ankle joint.

10. The doctors at CWH were:

- (i) Dr. GRO-D
- (ii) Dr. GRO-D,
- (iii) GRO-D
- (iv) Dr. Strevens,
- (v) Dr. GRO-D, and
- (vi) Dr. GRO-D

11. All these doctors were consultant haematologists who treated me over the years.

12. By 1982 the doctors at CWH had taught my mother how to inject my brother and I with FVIII products. By 1986, when I was 12 years old, I was able to treat myself. Simon and I were given the injections at home and my mother kept a log of all the dates and the names of the products used on the home treatment record sheets provided by CWH. My mother also recorded duplicate notes for her own keeping as she didn't trust the record keeping at the hospital. From 1982 until 1994 when I left home, me and my brother used bottles from the same Factor VII batches, therefore our treatment records showing batches supplied should match during this period.

13. Upon each visit at this hospital for treatment collection, my parents were given a form treatment to complete each time I had a bleed. This recorded the bleed location, amount of Factor VIII administered, batch number, manufacturer, and whether it was the first injection for that bleed, or follow-up treatment required for more severe bleeds.

14. From 1982, the need to visit CWH was reduced and I only attended for routine clinic appointments, blood tests, re-supply of Factor VIII products, or if I had particularly severe bleeds that required the opinion of a doctor to advise

on treatment in terms of Factor VIII dosage and how many follow-up injections should be administered.

15. My mother informs me that Simon and I were ill for a considerable part of 1982. Both of us tended to pick up general infections fairly quickly. These included colds, stomach aches, ear infections and other similar infections. I have no school photo from that year as a result of being absent due to illness.
16. My mother was introduced by the CWH to another mother whose son also attended the Haemophiliac Centre, as we all lived in GRO-C at the time. It was via this other mother that my parents found out that both me and my brother were HIV+. My parents were waiting for a train at GRO-C train station one day and bumped into this other mother. She asked my parents if they had had any letters from the hospital and my parents said they hadn't. She then told them that me and my brother were HIV+ then, as any Haemophiliacs that had tested negative were receiving letters confirming this. She added that almost everybody treated with Factor VIII at the CWH had been infected with HIV+, including her own son. At no point did the CWH ever ask my parents to attend the Haemophilia centre to inform them of our diagnosis.
17. At that time, we were never told that Simon and I were being tested for HIV, or Hepatitis. The doctors at CWH did not give my parents any information. The onus was placed on us to find out about the infection/s and what that meant when given positive results.

HIV

18. I believe that the staff at CWH told my parents that I had tested positive for HIV in or around 1986.
19. I do not know when I became infected with HIV, or Hepatitis C but I believe it was in or around 1982 when Simon and I were both ill with the general infections described above.

20. The doctors were not helpful. My parents made an appointment to see Dr Strevens following being informed that we were HIV+ by this other mother, but I do not know whether they actually saw this doctor. I do know that during the appointment the doctor never confirmed our HIV status and it was only after a Laboratory Technician at this hospital, a Mr Lavingdon, said to my parents, *"well you didn't ask, did you..?"* that it was strongly inferred that we were both HIV+. This was extremely cowardly, the hospital thought the prognosis for us was terminal at the time, and didn't want to have this conversation with my parents. We were left to go away and die.

21. By this reaction, it seems that it was taken for granted that all patients that were treated with FVIII products should have expected to be infected with HIV. Clearly, this was not the position.

22. The doctors should have arranged a consultation with my parents as soon as they became aware of the potential risks of Factor VIII to inform them of the situation. They should have engaged with my parents to advise of alternative therapies and the possibility of suspending Factor VIII treatment for all but for all but the most severe of bleeds and given my parents the information and choice of how to manage my haemophilia against the potential for infection. The doctors should have informed my parents, and gained their consent, to testing for HIV or other infections. They should have told my parents the nature of the infections, what treatment was available, if any, and how we should have managed these. They failed to do this completely. My parents left the CWH that day with the understanding that me and my brother (their only children) had just been given a terminal illness.

Hepatitis C

23. I do not know when the doctors confirmed that I was infected with Hepatitis C. I do know that the doctors informed my parents at a routine appointment that I was infected with Non-A Non-B Hepatitis. I believe my parents were

informed my brother may have Hepatitis in 1982. To my knowledge, the hospital never gave any useful information about either infection.

24. I was infected with both HIV and Hepatitis C but I have never been told which infection came first. I believe my brother was infected with Hepatitis C about 1982. This is because my mother confirmed it was in about these years his skin tone turned yellow indicating jaundice and abnormal liver function. My mother's notes confirmed that in April 1982 she was told that Simon may have Hepatitis. We also had illnesses at the time that were attributed to viruses, the symptoms of which included, lethargy, headaches, stomach pains, my mum was told this was '*migrane of the stomach*'. We also experienced '*rushing*' noises in our ears when receiving Factor VIII injections. No explanation was given at the hospital when this was raised.

Queen Elizabeth Hospital, Birmingham (QEH) (1994 – 2001).

25. In about 1994, I began a degree at a university in Birmingham and when I did, I started attending QEH. This was from the ages of 20 years to 27 years.
26. At QEH, I was attending appointments between 3 and 6 months for blood tests to monitor my HIV and Hepatitis C status. In 1995/6 following increased abnormalities in my liver function blood tests, my doctors recommended that I have a liver biopsy to get a better picture of the condition of my liver. I underwent a liver biopsy in the first year of my HND which required an overnight stay in hospital. The results showed that my liver was degrading and there was scarring and cirrhosis of the liver, they recommended that I start treatment for Hepatitis C as soon as possible.

Royal Free Hospital (RFH) (2001 – to date)

27. From about 2001, when I was 27 years old, I started attending RFH and I currently receive my appointments at this hospital.

28. Towards the end of 2018, I applied to CWH, QEH and RFH, my GP and the National Haemophilia Database (UKHCDO) for my medical notes. I have been told that my medical records from CWH and QEH have been largely destroyed to which **Exhibit WITN1389002** refers. I only received treatment records post 1987 from CWH (attached as **Exhibit WITN1389003**) that my mum filled out and returned to CWH, none of these mention American factor products being administered as Armour was administered to me between 1979 and 1985. I received limited notes from my GP (attached as **Exhibit WITN1389004**) and very limited records from the UKHCDO. In a letter dated the 22nd July 2019 I received further information from the UKHCDO (attached as **Exhibit WITN1389005**) dating back to 1978, but crucially this omits any mention of the US Armour Factor VII that my mother has recorded in her own duplicate records. I have received detailed records from the RFH.

Section 3. Other Infections

29. I believe I was also infected with Hepatitis B as a result of being treated with FVIII blood products but that I cleared it naturally.

30. I received a letter from the RFH in 2004 that I was treated with blood products from a donor who subsequently died from vCJD. It appears the hospital were sending letters to all those who were treated from that particular batch of treatment to put them on notice. I remember raising this at a routine appointment at RFH only to be told that they did not know whether it was transmissible from heat-treated blood products. Nothing further has ever developed from this and I am still unaware of the potential for developing vCJD.

Section 4. Consent

31. The doctors never told my parents that there were any risks involved with being treated with FVIII. The doctors did as they pleased. If the doctors had told us how the blood from the USA was sourced, who was providing it and

that it was not tested for contamination, my parents would have definitely refused it.

32. I know the doctors tested me for HIV and Non-A Non-B Hepatitis (Hepatitis C) without my, or my parents' knowledge or consent. How long they had been testing us I don't know, but as early as I can remember I have always had blood samples taken whenever visiting for consultant appointments.

33. I do not know whether the doctors tested or treated me for the purposes of research.

Section 5. Impact

Impact on me

34. I was 12 years old when my mother advised me I was HIV positive. I was not sure how I felt, apart from being shocked and numb. At that time, there was a considerable amount of negative media coverage about HIV and AIDS and my parents believed that Simon and I were going to die. Even though I was still very young, I knew what was likely to happen to me and also to Simon. I also knew I would never be able to have children. My mother had to tell me to keep this a secret from Simon who was 9 years old at the time.

35. My parents were devastated at the thought that they were going to lose both their sons to AIDS. I do not believe there were any drugs available at the time to help to treat the infection. My parents felt helpless but did their best to hide their true feelings from us. They did their best to continue as normal because that was their way of trying to protect us.

36. Now I am a father of two boys, the same age as me and my brother when we believe we were infected. I can relate to the utter devastation that must have been felt by my parents, to be told your children are going to slowly die from an incurable disease.

Support

37. I had to deal with everything on my own. CWH offered no support whatsoever to our family. If my mother found out something from the hospital and told me she then told me not to tell Simon. My mother never told the school that we were infected with HIV because of the way the newspapers were reporting. People who it was known were infected with HIV were victimised, graffiti was painted on their houses and other people withdrew their children from schools with haemophiliacs in, or had children who were HIV in. My mother was worried that Simon and I would be bullied at school because of it and therefore no-one outside the four of us ever knew.

38. It was very difficult growing up not knowing whether I was going to survive when so many others around me were dying of AIDS. I also felt very sad that I would never have children of my own. I believe I suffered from depression from my early teens to my mid-twenties as a result of my infections and the lack of support available to me.

Family

39. My parents did not tell anyone about my HIV status, not even close family. I felt lonely and very isolated because I thought I was going to die and there was no one I could trust to talk to. There was no support offered from anywhere. My parents did not talk about it at home as it would have upset everyone. It was the elephant in the room when anything AIDS related came on television in the 80s and early 90s. I believe the lack of support affected my relationships with my family as I became introverted and never discussed my feelings with them for fear of breaking down and crying.

Education

40. Being infected with HIV badly affected my education. This is because I saw little point in studying and working hard if I wasn't going to live to get a job or have a career. At the time I was diagnosed the prognosis was that once you shown symptoms of full blown AIDS you had about two years to live. GRO-C

GRO-C

I had little thought of the future at the time and tried to experience as much as I could in the time I had left.

41. I remember that the Haemophilia Society used to organise an activity holiday during Summer in North Wales, where I made friends with other haemophiliacs. I remember sometimes, probably when I was about 14/15, we would talk about what we would do if we went full blown. If we would see it out to the end, or if we would end our lives before we got really ill and how we would do it. When other children our age were out playing on their bikes or playing football, we were discussing how we would kill ourselves. I sometimes wonder, how many of those boys are still alive.
42. I used to stay at home a lot more during secondary school because I felt isolated and did not have a normal experience growing up as a teenager. I thought a lot about dying and missing out on the normal things people do such as having families. I really thought I wasn't going to get to 30.
43. I didn't do any revision for my GCSEs and obtained five GCSEs at 16, I had to re-sit my English exam the following year to pass. I stayed on at my school sixth form to do 'A' Levels and failed all of them after two years. I then went to college in Leamington Spa to do an OND in Building Studies, but I hardly turned up and failed after two years, I was 20 at the time. I spent the following year with friends in Birmingham living off benefits and partying. It was only toward the end of this year that I thought I might get to live a bit longer than I have thought and perhaps I should do something about it.
44. I went to university in Birmingham in 1994 to do a two year HND in Building Studies. It was during this time that I had to start my treatment for my hepatitis C. I went on to pass my HND and also pass a degree in building surveying in 1999.

Relationships

45. My relationships with girls was non-existent in my teenage years and early 20s because I was afraid of them telling anyone about my infections. I feared that if they found out, they would tell other people and I couldn't risk that. This prevented me from forming normal relationships. I think the stigma of HIV was lesser in the late 90s as treatments became available, but I had been conditioned to never, ever, tell anyone and this has remained with me for the whole of my life. It is only in the past 12 months that I have made my infections status public.

46. I got married and had children later than I would have otherwise done. I feel I lost my teenage years and everything happened much later for me, as if my life had been suspended for 15 years. It was only when I lived into my early 20s that I began to think I may have longer to live than the doctors and I had thought.

47. My wife and I wanted to have children. We went through a course of assisted conception in the form of sperm washing. We obtained NHS funding for the first cycle of treatment. My wife got pregnant on the second attempt and that is how we got pregnant with our first child. Three years later, we wanted another child and Lewisham Primary Care Trust refused to fund it because our circumstances were "*not exceptional enough*"! I attach a copy of this letter at **Exhibit WITN1389006**. This application for funding was accompanied with supporting letters from my HIV consultant, confirming I had acquired HIV via NHS supplied blood products and noting this was to reduce the risk of HIV transmission to my Wife. We had to self-fund for another cycle of assisted conception which costed around £4,000.

Employment

48. In terms of my employment, my career has not progressed the way that it should have had I not been infected. I didn't get my first full time job until I was 27, for this reason I am behind people of a similar age to me, both in terms of seniority and earnings. This has meant I have not been able to contribute to my pension as much as I could have, or save as much. I wasn't

able to buy my first property until I was 29, using the last of my ex-gratia payment received from the Government in the early 90s as a deposit.

49. I feel more resilient now and I feel like I can take and leave jobs that I am not happy with because I know that there is more to life than earning money and I have to use the time I have to maintain a good work-life balance. I do not think I would have moved from one job to another so quickly if I had not been through the experience of growing up with HIV or Hepatitis C.

Section 6. Treatment/Care/Support

50. I do not know how much doctors knew about HIV and Hepatitis C in the 1980s. Although, they tested both me and my brother without the consent of our parents as we were always having blood tests at hospital appointments, so they knew a lot more than we did. At the time, me or my parents were not offered any form of support whether psychological, or just someone to go to talk to. I know there was no medication that was effective at treating AIDS and that had I developed AIDS I would have died. During my time at the QEH and the RFH the doctors informed me that my CD4 count was normal and my viral load was undetectable. I do not know whether that has always been the case. I always felt a sense of relief all thought my time at the QEH at getting those results every few months.

51. I am not taking medication to control my HIV because currently my CD4 count is within an acceptable level and my viral load remains undetectable.

52. In 1995 during my HND, I started a course of Ribavirin and Interferon treatment to try and clear my Hepatitis C. I was made aware by my doctor that the side effects of the treatments, Interferon injections three times a week and Ribavirin tablets five a day in the morning and at night, could be quite severe and that about 50% of people were unable to complete the 12 month. The side effects of Interferon included flu-like symptoms, tiredness, aches, pains, colds and shivering for about 24 hours following the injections. I

was lucky to be able to finish the course, which was successful and cleared the hepatitis C.

Current medical condition

53. My short term memory is terrible and I believe this is a result of the Hepatitis C and/or Interferon/Ribavirin treatment. Whenever my wife asks me to do some shopping, or do something, I always forget what I need to buy very quickly.

54. I was not able to have regular immunisations at school because the doctors didn't know how the HIV would interact with the live viruses in some immunisations, if they might kick start the HIV into AIDS. My dental treatment was also transferred to the hospitals. I believe this was to prevent me from infecting other patients, or the dentists treating me in standard dental practices with HIV. They could implement better barrier processes and the dentists were more aware of HIV transmission in the hospitals.

55. In 1990, when I was 16, I underwent a psychological assessment. This was for the HIV class action. I have a copy of that report, which is exhibited to both of my parent's witness statements. It confirms that I thought I had a 50/50 chance of survival and that I was unlikely to ever have children or get married. It also confirms how upset I got when these subjects were brought up.

56. I have never been offered any counselling in relation to my infections.

Section 7. Financial Assistance

57. In 1990, I received a £20,000 following settlement of the HIV Litigation. About 18 months later, I received another payment of £20,000. These payments were made ex-gratia.

58. The Macfarlane trust was set up as a result of the 1990 class action. I currently receive £38,000 per year as a result of my HIV and Hepatitis C infection. This payment has only recently been increased as a direct result of pressure on the Government from the various contaminated blood support groups, some MPs and the publicity of the Inquiry. This payment is made by the EIBSS which is the successor to the Macfarlane Trust.

59. I used to receive '*top-up*' payments of £100 per month per child as a non-discretionary payment. However, this was changed to a discretionary payment following a review by EIBSS, at which point we were told we no longer qualified because it was now means tested.

Section 8. Other Issues

60. I have no doubt the hospitals and UKHCDO have destroyed crucial evidence that is relevant to the Inquiry, or have placed it in locations difficult to locate. All records I have received from the UKHCDO and CWH do not make mention of issuing American blood products to me or my brother, our mother kept detailed duplicate records showing we were issued with Armour products from 1979 through to 1985 on numerous occasions prior to our diagnosis.

61. My brother was involved in a class action against the American pharmaceutical companies in America, but I was not able to join because I was informed that my relevant medical records from the CWH had been destroyed. The CWH and QEH have informed in me in writing that my records have been destroyed.

62. I think it is disgraceful how my parents found out about how Simon and I were infected by FVIII blood products. The CWH even had the affront to bring the Armour representative into a hospital appointment to say it wasn't their products that had given us HIV and my parents told me that they were expected to feel sorry for this guy.

63. Even after we had been diagnosed with HIV the doctors at the CWH tried to give my parents Armour Factor VIII, I believe to use their stocks up. Mr Lavingdon, the lab technician who issued the Factor VIII said '*Well they're already infected*'. The callousness of it is staggering. My parents flatly refused to take it and insisted on products sourced from the UK which were eventually provided.

Anonymity, disclosure and redaction

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

I am prepared 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

Matthew Merry

Dated 31 July 2019