Witness Name: **Matthew JOHNSON**
Statement No.: **W1057001**
Exhibits: **None**
Dated: **19 December 2018**

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MATTHEW JOHNSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16 October 2018.

I, Matthew Johnson, will say as follows: -

Introduction

1. My name is Matthew Johnson. My date of birth and address are known to the Inquiry. I suffer from severe Haemophilia B and have less than ½% of normal Factor IX levels. I intend to speak about my condition, my treatment with Factor IX concentrates and my subsequent infection with HCV and exposure to NvCJD. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and continues to have on me, my partner and our lives together.

2. I was diagnosed with severe Haemophilia B in November 1981 at the age of 1. My diagnosis followed a fall where I cut the inside of my mouth and had to have two teeth removed; the surgeons who removed by teeth and stitched the wound noticed that I was bleeding excessively and they tested

my blood for clotting agent levels. I was treated with fresh frozen plasma and ultimately released from hospital and referred to the care of Dr Rizza at the Oxford Haemophilia Centre.

How Infected

3. Following my diagnosis and referral to Dr Rizza, I began to be treated with Factor IX concentrates every time that I had a bleed which was approximately once per month; it is unclear from my medical records but at some point between November 1981 and September 1983, I had begun to be treated with Factor IX concentrates prophylactically i.e. 20 units of concentrates were administered to me by my mother each week.

4. I understand that my mother and father gave consent for me to be treated with Factor IX concentrates following a conversation with Dr Rizza where they were assured that, whilst there was a risk of hepatitic viruses, even if I were to contract hepatitis, it would be no more severe than a bad cold.

5. It is (again) unclear from my medical records where the concentrates administered to me were sourced from but there is a letter dated 11 August 1986 which my then doctor (Dr J.M. Matthews) wrote for me to carry on a holiday to France with my parents; the note says that I am being treated with NHS Factor IX concentrates and that, by this time, I was receiving 600 units per week (again, prophylactically).

6. Amongst my medical notes is a table which records the concentrates I was given between 1981 and 2000; I do not believe that this record is complete but there appears, from the batch numbers, to be four different products administered to me throughout the record; I set out examples of their batch numbers in the table below:-

Year(s)	Type of material	Batch no. (sample)	Bottle no. (sample)
1981-1992	9D or 9A	2179	811012AW11B
1993-1994	NHS	FJA4164	(H/T)
1994	9MC	FJM4323	
1996-2000	Replemine	FJTN5118	

7. I was predominantly treated by Dr Rizza and Dr Matthews at the Oxford Haemophilia Centre but I was also treated at my local hospital, Milton Keynes Hospital and I underwent surgery in 1982 and 1984 at the Radcliffe Hospital to treat an unrelated, congenital condition. During my treatments at the Radcliffe Hospital, I was given large doses of concentrates pre and post operatively (at the instruction of Dr Matthews) to reduce the risks of the surgery and subsequent bleeds.

8. I believe that I was exposed to contaminated concentrates at some point between 1981 (my first treatment) and 1984; because of the sheer volume of concentrates that were administered to me and the incomplete nature of my medical records (as can be seen from the table above) I am unable to set out a precise date.

9. I am often described in my medical records as extremely short and underweight for my age; I understand from recent medical research that impaired growth can be a symptom in children with hepatitis and I believe it more likely than not that I was infected if not from my first exposure to concentrates then shortly thereafter.

10. Given the period of time within which I was infected and the fact that I was a patient of Dr Rizza and Dr Matthews, I believe that at least in some instances, I may have been treated with concentrates upon which heat treatment processes had been trialled. In short, I believe I may have been a previously untreated patient/P.U.P. and may have been

used as a guinea pig to test the effectiveness of developing pasteurisation techniques.

11. I have no way to confirm my belief as there is no reference within my medical records and my parents were not consulted in any way. Indeed, the only information given to my parents about hepatitis until 1991 was that it was no more severe than a bad cold.

12. There is no mention in my medical records of consent being sought or of any mention being made to my parents about testing me for HCV but there is a letter dated 18 June 1990 which notes in passing that I had been tested for HCV in September 1989 and had been found to be *"Hep C Ab positive from a sample taken"*.

13. As such, I was known to my doctors to be HCV positive from the age of 8; my parents were not notified until 27 January 1992 when I attended a routine review appointment with Dr Rizza and he discussed my hepatitis diagnosis with my mother. A period of two and a half years passed between me being diagnosed with HCV and my parents being told of my infection.

14. The delay in informing my parents of my infection was profoundly unethical and causes me an enormous amount of anger; not only was I potentially not being treated adequately because my HCV status was kept secret from me but I also risked (on the knowledge at the time) infecting members of my family unknowingly.

15. I can think of no reason why my HCV status was not disclosed to my parents immediately after my test results were known; I can also think of no good reason why my parents' consent to test me for HCV in the first place was not sought.

16. At my appointment on 27 January 1992, Dr Rizza also discussed with my mother the prospect of moving me to high purity concentrates within

the next 12 months; on my reading of my records, I think this switch ended up happening in or around 1994 when I was moved to Replenine.

17. From February 1998 I was asking about the possibility of being moved to recombinant treatments; I was told that recombinants were likely to be introduced in June 1998 but that I was unlikely to be eligible because I was already infected with HCV.

18. My treatment was not switched to recombinant Factor IX until 2004, six years after my initial request and years after recombinant treatments were made available universally to Scottish and Welsh haemophiliacs. English patients were not given recombinant products as a cost saving measure by the Department of Health; I find it outrageous that I was potentially placed in continuing jeopardy as part of a cost saving exercise.

19. At about this time in 1998, I was also seen by Dr Keeling at the Oxford Haemophilia Centre and was told that there was a risk that I had been exposed to NvCJD through the concentrates I had been treated with. As a result of this meeting my treatment was changed from Replenine to Alphanine.

Other Infections

20. On 20 September 2004, I was sent a letter by Oxford Radcliffe Hospitals again explaining that I may have been exposed to NvCJD, that I was considered "at risk" for public health purposes and that I would need to inform people such as my dentist so that special measures could be taken when dealing with me.

21. I was invited to complete an information sheet indicating whether I wished to know whether I had been treated with implicated batches of

factor concentrates; I did so and followed this up with an email on 26 October 2004 requesting the number of times I had been treated with implicated concentrates.

22. My email was answered the same day by a letter from Dr Giangrande confirming that I was known to have been exposed to NvCJD twice – between February and April 1995 and between May and July 1997.

23. In the initial letter of 20 September 2004, I was given an information leaflet but this dealt primarily with how the situation had come about and what risk avoidance measures I should now take; it did not tell me what to expect if I developed NvCJD.

24. The idea of developing symptoms of NvCJD terrifies me and I find it difficult to speak about; the psychological impact of knowing of my exposure is overwhelming.

25. Following the confirmation that I had been exposed to NvCJD and coupled with my ongoing HCV infection, I spiralled into depression and began drinking significantly more than I had historically; on 11 November 2004. Dr Abigail Jones at the Oxford Haemophilia Centre wrote to my GP indicating that I should undergo a course of counselling and be assessed for a course of anti-depressants.

26. Exposure to NvCJD is one of the hardest things I have had to deal with; because I wasn't given information about the nature of the condition, I conducted my own research which often led me to the most extreme stories. To this day, the thought of developing NvCJD terrifies me and can lead to protracted depressive moods.

Consent

27. As I set out above, my treatment with factor concentrates commenced with my parents' consent BUT that consent was procured with a lie – it was not informed consent.

28. By the time I was treated with concentrates for the first time, NANB hepatitis was well known of and it was also well known that its affects were far more severe than a bad cold. Equally, it was well known that by giving me concentrates, I was almost guaranteed to be infected with at least HCV if not HIV as well.

29. My parents have been crippled with guilt from having given their consent to me being treated with factor concentrates GRO-D GRO-D

30. My parents would never have consented to me being treated with concentrates had they known the true risks; whilst it would have made life difficult, I would nevertheless have been capable of being treated with far safer cryoprecipitate.

31. My parents would certainly never have consented (and did never consent) to me being treated with experimental concentrates if, as I suspect, it is shown that I was a P.U.P.

32. As to testing me for HCV, no consent was sought whatsoever and obviously, no form of pre or post-test counselling was therefore given. Not only was consent not sought to test me but, as I detail above, I was not even given the results of the test until years later.

Impact

33. Firstly, the impact of my HCV infection was of itself, devastating; I have stage two fibrosis of the liver and my chances of developing liver cancer are significantly enhanced – in short, my life has been cut short because I was infected with HCV by the NHS.

34. The only chance at me given some of this lost time back is for me to be given a liver transplant though I understand that this is unlikely to happen. I note that in America, haemophiliacs who have been infected through factor concentrates are fast-tracked for liver transplants and this seems to me to be the least that a government could do to put right some of the damage done through infected blood products.

35. HCV left me constantly fatigued, feeling alone, depressed and angry; I pushed away the people closest to me through fear of infecting them.

36. More than this, I had to worry about the shame my sister must carry in having a brother infected with HCV as well as my parents' overpowering guilt at having effectively consented to me being infected.

37. The damage done to me by HCV was matched by its cure. In September 2005 I began a year's treatment with Interferon and Ribavirin aimed at curing me of HCV; my levels of HCV are now undetectable which is the closest that I can come to saying I have been cured.

38. The treatment itself was horrific, it left me so fatigued that I could not drive and even now, I often need to sleep in the afternoon to have enough energy to see through the day.

39. The mental effects of the treatment were profound; I became deeply depressed, my temperament has permanently altered to become more irritable and I often had suicidal thoughts.

40. The impact of HCV during my school years was extreme; I thought I was going to die very young so I never saw any point in putting in the effort.

41. My infection with HCV disadvantaged me enormously in the work place. I have a good job but I was frequently offered promotions and options to move to other positions which I was unable to take because I need to work flexible times from home so that I can sleep regularly. I have been offered positions which would pay me more than double the salary I currently receive but which, as a direct result of my infection, I could not take.

42. My main concern financially is that because of the damage done to me by HCV, I will not have enough resources to leave adequate provision for my partner and our children when I die. My life has been truncated and I don't have the same 50 year period to build something up to leave for my children – my EIBBS payments will not (as I understand it) continue after my death and my partner and our children will be left to fend for themselves.

43. Turning to my exposure to NvCJD, as I set out in the earlier parts of this statement, the psychological effect has been catastrophic and I live in constant terror of developing symptoms.

44. Learning that I certainly had been exposed launched me into such depression that I simply could not function.

45. Both the HCV infection and the exposure to NvCJD have led to other areas of my healthcare changing in small ways which have big psychological consequences. For instance, when I have blood taken now, stickers are placed all over the sample saying "danger of infection" – this leaves you feeling dirty and there is simply no reason why any necessary warnings cannot be placed on samples after a patient has left the room.

46. Equally, I have had to change dental surgeries having been refused treatment on three separate occasions because of my exposure to NvCJD.

47. Whenever I have any kind of procedure (dental, surgical or otherwise) which requires reusable tools, I am left until the last procedure of day so that the tools can be specially cleaned or destroyed – the psychological effect of this is horrible.

Treatment/Care/Support

48. I have already set out the various difficulties I have had in obtaining treatment. With particular reference to the delay to move me to recombinant concentrates, I find it abhorrent that the attitude taken by the government seems to have been that it was ok to give me the old risky stuff because they had already infected me with HCV. This is particularly disgusting at a time when the government was coming to understand the risk of NvCJD, a new pathogen that was blood borne and which was previously unknown – the potential for other unknown diseases to be carried through blood was entirely unknown and every haemophiliac should have been immediately moved to recombinant concentrates.

49. No form of counselling has ever been offered to me specifically to deal with my infection with HCV (or indeed, my exposure to NvCJD). I have had counselling courses but only as a result of the depression that has ensued from my infection/exposure and not to deal with the fact of being infected/exposed in the first instance.

Financial Assistance

50. I originally received a payment of £20,000 from the Caxton Foundation with a small monthly payment on top; by 2017 this had increased (under EIBSS) to £252.50 per month.

51. In February 2018, I was accepted into EIBSS' Special Category Mechanism which increased my monthly payments to £1,262.50. I am

also eligible to apply for a one-off payment of £50,000 though I have not done so yet.

52. Obtaining payments from EIBSS (and the trusts preceding it) is needlessly difficult and you are made to feel as though you are begging from the state. The forms required to obtain any kind of payment are huge when really, it is evident from my medical records that I have been infected with HCV by the NHS – there should be no need to complete any kind of form.

53. I am lucky in some respects that I am capable of completing the forms; this will certainly not be the case for a number of infected victims – there should be communication between the NHS and DWP so that this unnecessary burden is immediately lifted.

Other Issues

54. Simply, my life has been destroyed by the acts and omissions of the very people who were meant to care for me.

55. Similarly, the lives of my parents have been destroyed by the guilt they live with through their perception that they consented to the treatment that infected me – as I set out above, I do not believe that they gave any meaningful form of consent.

56. It is not only our lives that have been affected but the lives of my children will be infected – bluntly, I will not be there to support them (in every sense of the word) for as long as I should be.

57. I want this Inquiry to find out who did what wrong and when and I want those people to be held to account. Where people have been more than simply negligent, I want this inquiry to recommend criminal prosecutions.

58. I also want this Inquiry to make recommendations for proper compensation; I want to have at least some peace from knowing that when I do die, my partner and children will be cared for.

Statement of Truth

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

Signed GRO-C

Dated 19 December 2018