Witness Name: Kim Johnson
Statement No.: WITN1062001
Exhibits: **None**
Dated: 19 November 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KIM JOHNSON

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

I, Kim Johnson, will say as follows: -

Introduction

1. My name is Kim Johnson. My date of birth and address are known to the Inquiry. I am the mother of Matthew Johnson and I intend to speak about my son and his infection with HCV and exposure to vCJD. In particular, the nature of if his illness, how the illness affected him, the treatment received and the impact it had on him.

How Affected

2. Matthew was born in 1980; when he was 10 months old, he fell and hit his face, Matthew's face was quite badly injured; the injury would not stop bleeding so we took him to A&E where he had to have two teeth removed and his gums had to be stitched back together.

3. The surgeons who removed Matthew's teeth noted that he bled a lot during the surgery and they treated him with fresh frozen plasma; Matthew's clotting levels were tested at the hospital and he was diagnosed with severe haemophilia B.

4. There was no known family history of haemophilia though I and my two daughters have subsequently been tested and found to be carriers of haemophilia B.

5. Following Matthew's diagnosis, he was referred to Dr Rizza at the Oxford Haemophilia Centre ("OHC") and to the best of my recollection, immediately began to be treated with factor concentrates whenever he had a bleed, this was on average, once a month and the treatments took place at OHC.

6. Before Matthew was first treated with concentrates at OHC, I cannot remember any conversation with Dr Rizza or anyone else there about what concentrates were or how they differed from other blood products. I am certain that there was no conversation initially about the risks of concentrates or how those risks differed from fresh frozen plasma or cryoprecipitate. My husband and I were simply told that Matthew needed the medicine they were giving him to stop him bleeding internally.

7. Subsequently, there was a conversation with Dr Rizza where we were told that there was a risk of hepatitis but that we shouldn't worry because even if Matthew got hepatitis then it would only be like a bad cold and if he didn't have the concentrates then he would be crippled before he was 30.

8. In or around early 1983, Matthew began to be treated prophylactically with concentrates; I was taught how to inject Matthew at OHC and I would administer his factor IX on a twice weekly basis at home.

9. In 1986, my husband and I had become aware of reports of haemophiliacs becoming infected with AIDS and we went to OHC and spoke with Dr Matthews. Dr Matthews told us that concentrates were now heat treated to remove AIDS but that this hadn't always been the case and so Matthew began to be tested every six months to see whether he had been infected.

10. I cannot remember if it was at this meeting or a subsequent meeting with Dr Matthews but it was around the same time in 1986 when we were told that Matthew had been infected with non-a-non-b hepatitis. We asked what this was and again, we were assured that it was nothing more than a bad cold at worse and even if the symptoms ever developed then they would clear within a month or so.

11. It was not until 1992 that we were told that Matthew had HCV, that this was the new name for non-a-non-b hepatitis and that it was potentially fatal.

Other Infections

12. In 1998, prior to Matthew's 18th birthday, we were told that Matthew had received concentrates from a donor who had gone on to develop vCJD.

13. My husband and I felt unable to tell Matthew because the effect on his mental wellbeing (which I will detail below) from being told of his HCV infection was profound; I simply did not think Matthew could take being told of this new threat.

14. Matthew did not find out about his exposure to vCJD until 2004.

Consent

15. My husband and I gave our uninformed consent to Matthew's treatments and we also consented to him being tested for HIV. I do not

recall consenting to Matthew being tested for HCV, I simply remember being told that he had been infected.

16. Had we known of the real risks of concentrates, had we known of the alternatives (FFP and Cryoprecipitate) and had we known of the comparative risks of those alternatives; in short, if we had been given the opportunity to give informed consent, it would not have been given.

Impact

17. The impact upon Matthew of being infected with HCV was terrible; it was terrible for him knowing that he had an infection which could kill him and would probably shorten his life and his suffering was compounded by the worry he had for us (his parents) and his sisters. Matthew has often worried about the stigma his sisters might suffer if it became known that he was infected and he has worried about me and his father because of the psychological effect it has had on us.

18. The side effects of the treatment Matthew received for HCV were appalling and he has been left with severe fatigue; he has done so well professionally but he could have done so much better if he was able to go to work like a healthy person can – instead, he has to stay at a level where he can work from home and sleep as and when he needs to.

19. The impact of HCV and its treatment have paled in comparison to the effects of Matthew discovering that he has been exposed to vCJD. Matthew is terrified by vCJD and he can often slip into deep depressions which take a long time to come out of – Matthew is dependent on anti-depressants and has had periods where he was so low that he contemplated suicide.

20. Matthew was a carefree, sensitive boy who, through infected blood products, has become a man that is outwardly coping but who struggles enormously, every day with his infection and exposure.

21. The impact on me has been profound. The first time I had to deal with the fact that Matthew's treatments were dangerous was in 1986 when we went to OHC about the risk of AIDS and we were told that there was a risk and that Matthew had to be tested every six months.

22. We were told not to tell people that Matthew was a haemophiliac because of the connection that was being drawn between haemophiliacs and AIDS and we were also told not to tell anyone that Matthew was being routinely tested for it.

23. The time during which Matthew was being tested for HIV was horrendous; every time I rang for Matthew's test results I felt physically sick and at the same time I was still having to inject Matthew with his treatments knowing that every time I did, I didn't know what I was putting inside his body.

24. Finding out the non-a-non-b hepatitis was in fact a lethal infection rather than the benign condition we were told it was, was awful. It was particularly bad for me because when I thought back to when we were told about non-a-non-b, it was shortly after Matthew began home treatment. It always seemed to me that I had infected Matthew with HCV and I felt so guilty.

25. Finding out that I had passed haemophilia to Matthew added to my guilt; it has been terrible to watch Matthew struggle first with haemophilia, then HCV and its treatment and then vCJD exposure.

26. The combined effect of constantly worrying about Matthew contracting HIV, trying to stay strong to support his mental well-being and living with the guilt of possibly having given him the treatments that infected him led to me suffering panic attacks. I was ultimately prescribed beta-blockers and referred for counselling to try to deal with my own mental health problems.

Treatment/Care/Support

27. I know that Matthew has detailed the difficulties he has with dentists and other treatments in his own statement but the main difficulty that I have experienced with Matthew was his struggle to get recombinant treatment.

28. When recombinant was first introduced we asked Matthew's doctors to prescribe it for him straight away but we were told that Matthew would not be able to have it for three reasons: (1) that he lived in England and recombinant would only be available in Scotland and Wales initially; (2) Matthew would be too old by a matter of a couple of months when the treatment was introduced in England; and (3) he would be ineligible in any event because he had already been infected with HCV.

29. I was appalled that whoever came up with these rules thought it was ok to carry on treating people with products which had previously infected people just because they had already been infected.

30. We began investigating moving to Wales just so that Matthew could get the safest treatment possible, but Matthew's doctors told us that this wouldn't work because we were trying to "cheat the system".

31. In the end, Matthew was finally given recombinant in 2004 – had he been given it when we first asked for it then he would not have had a second exposure to vCJD.

Financial Assistance

32. I understand that Matthew has received a lump sum payment from the Skipton fund and receives monthly support payments, under the special category mechanism, from EIBSS.

33. I am not aware of any specific problems that Matthew has experienced with support payments other than the fact that the application process was cumbersome and complex.

Other Issues

34. Matthew was a young child when he was infected with HCV and if we had only been told the truth and asked for our informed consent then that might never have been the case.

35. If we had been told that there were safer alternatives to concentrates, if we were told that there were risks to concentrates, we would never have allowed Matthew to be treated in the way he was.

36. I feel like I was lied to consistently by Matthew's doctors – I was lied to by omission when I was led to believe that there was no alternative to concentrates and I was lied to directly when I was told that non-a-non-b hepatitis was nothing more than a cold; it was known long before 1986 the HCV was lethal.

Statement of Truth

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

Signed GRO-C

Dated 19/11/2019.