Witness Name: Mark Johnson
Statement No.: WITN1061001
Exhibits: **None**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARK JOHNSON

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

I, Mark Johnson, will say as follows: -

Introduction

My name is Mark Johnson. My date of birth and address are known to the Inquiry. I am the father of Matthew Johnson. I intend to speak about Matthew who is a haemophiliac who has been infected with HCV and exposed to vCJD.

How Affected

1. Matthew was 10 months old when he was diagnosed with haemophilia B; he had fallen and cut the inside of his mouth. When Matthew's mouth didn't stop bleeding, we took him to A&E and he was diagnosed and referred to Dr Rizza at the Oxford Haemophilia Centre ("OHC").

2. Matthew was treated with fresh frozen plasma on that first occasion but after seeing Dr Rizza, he began to be treated with factor concentrates, first when he had bleeds (around once a month) and then from around 1983, prophylactically.

3. There was a conversation with Dr Rizza but not one of our first conversations, perhaps around the time Matthew began prophylactic treatment, about there being a risk of infection from concentrates.

4. As I recall, we were told that it was possible that Matthew could catch hepatitis from the treatments but that even if he did, it would be nothing to worry about, it would be like a bad cold.

5. The risk as presented by Dr Rizza was set by him, against the benefits of the concentrates – Matthew was an active boy, and we were told that the concentrate would mitigate against him developing arthritis or having joint problems later in life.

6. When presented with the choice of Matthew being crippled by his 30s or having to deal with a bad cold, there was always only one choice that my wife and I were going to make.

7. I can say with certainty that Matthew was infected with HCV at some point between 1981 and 1984 though I now understand that it was likely his very first treatment with concentrates in 1981 that led to him becoming infected.

8. In or around 1986, we had a meeting with Dr Matthews at OHC and we were told that Matthew had non-a-non-b hepatitis (NANB), again we were told that it was nothing to worry about and symptoms might never develop.

9. As I recall, this particular meeting with Dr Matthews had been arranged at our request because my wife and I had heard about the risk of AIDS to haemophiliacs and we wanted to understand what risk Matthew faced. As such, we were far more concerned with the AIDS risk than being told

that Matthew had NANB which, even if it did give symptoms, would be nothing more than a cold.

10. We were eventually told, in 1992, that NANB was now called HCV and that far from being a benign condition, was life limiting and fatal.

Other Infections

11. After we were told that Matthew had HCV and that it was lethal, we started to have conversations about purer concentrates and in around 1994, Mattthew was moved on to Replenine. In 1998, we heard about recombinant and immediately asked for Matthew to be moved to it as we understood that it was the safest treatment possible.

12. We were told that Matthew was unlikely to be eligible for recombinant because he was too old by a matter of months and because he was already infected with HCV. We understood that the situation was different in Wales and that recombinant was universally available. When I broached moving to Wales to ensure that Matthew got the safest treatment, I was told that it would be pointless because efforts to "cheat the system" wouldn't succeed.

13. Later in 1998, we were attended an appointment with Dr Keeling at OHC where we were told that Matthew's time on Replenine saw him exposed to vCJD twice, in 1995 and 1997.

14. Matthew's exposure to CJD made the argument that he should be on recombinant even clearer for me – Replenine was supposed to be high purity and that is what had caused his exposure to CJD. In the end, Matthew wasn't given recombinant but was switched to Alphanine.

15. Matthew was ultimately switched to recombinant in 2004.

Consent

16. My wife and I consented to Matthew being treated with concentrates but only because of how the consent was obtained by Dr Rizza. The issue was framed for us as a choice between Matthew being crippled or taking a low risk. In this scenario, no reasonable parent is going to refuse their consent.

17. Had we known that the concentrates would without doubt give Matthew HCV, had we known that the concentrates stood a good chance of giving Matthew HIV and had we known later, that the concentrates would expose Matthew to vCJD then my consent would not have been given.

18. As to consent for testing, we certainly consented to Matthew being tested for HIV because we initiated the discussions with OHC about the HIV risk but I do not recall ever consenting to Matthew being tested for any other viruses or infections including HCV.

Impact

19. The impact of HCV on Matthew has been terrible as have been the lasting consequences of the treatment he received for it. Matthew has stage two fibrosis of the liver; he has a greatly enhanced chance of developing liver cancer.

20. As a result of the treatment Matthew received for HCV, he is left with extreme chronic fatigue which has limited his professional development extremely – he can only take positions where he can work flexibly as he often needs to sleep in the afternoons.

21. The impact of exposure to vCJD has perhaps been the worst for Matthew. We didn't tell Matthew about the exposures (we had been alone when we were told in 1998) but he found out through a letter in 2004. Matthew has a terrible fear of developing CJD and, together with the mental impact of the HCV treatment, leads him to terrible depressions. Matthew is dependent on antidepressants.

22. The impact on me and my wife has been bad – my wife has had to be treated for anxiety in the past and has had counselling to deal with the guilt she feels for having been the one to administer concentrates to Matthew and for haemophilia having come to Matthew in the first place through her genes. Her guilt is obviously misplaced but that does not stop her feeling it.

23. For me, I have dealt with trying to support Matthew through everything that he has had to face whilst supporting my wife and simultaneously trying to shield our other children from all that had gone wrong. It has not been easy.

Treatment/Care/Support

24. The major difficulty Matthew has always had has been to obtain recombinant treatments. I don't think we ever really understood that there was a risk from concentrates until 1986 and even then, we were reassured that heat treatment had made the products safe. In 1992, when we came to understand that Matthew had been infected with something dangerous, a twelve-year struggle began for Matthew to be moved to the safest treatments. It is ironic that Matthew was exposed to vCJD whilst on the safest treatment available at the time; for me, this just goes to show that haemophiliacs can never be 100% confident in the safety of their treatments.

25. I know that Matt has had a few difficulties in obtaining other types of treatments and particularly, dental care but I think his biggest trouble is that he is scheduled for treatments as the last in the list because of he has been exposed to vCJD. I don't think it is particularly the fact that he is treated last that causes the problem, it is the reason why he is treated last which adds to his anxieties and fears about vCJD.

Financial Assistance

26. Matthew has received a lump sum payment and receives monthly support payments; I'm not aware of him having any difficulties in dealing with the trusts or EIBSS.

Other Issues

27. Our family's lives have all been affected by Matthew's infection; Matthew has to suffer with the aftermath of HCV and exposure to vCJD whilst dealing with the consequences of haemophilia – contrary to Dr Rizza's advice, the concentrates haven't saved Matthew from joint problems and he has had to have his ankle fused.

28. Our daughters have been robbed of the happy brother they should have had. My wife and I are racked with guilt and it has been horrible to watch my son struggle for so long and continue to struggle now.

Statement of Truth

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

Signed GRO-C

Dated 21st November 2019