Witness Name: GRO-B
Statement No: WITN4722001
Exhibits: 0
Dated: November 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My full name is GRO-B I was born on 1950 and I live at GRO-B.

2. My son, GRO-B: S (born on GRO-B) was infected with the Hepatitis C Virus (HCV) through contaminated Factor VIII (FVIII) concentrate. S has provided his own Witness Statement to the Inquiry (WITN GRO-B.

3. This witness statement has been prepared without the benefit of access to my son's full medical records albeit I refer to S's UKHCDO record at paragraphs 6 and 8 of this Statement.

Section 2. How Affected

4. S was misdiagnosed with mild Haemophilia A at approximately 6 weeks from birth. He was admitted to Birmingham Children's Hospital (BCH) with

projectile vomiting and was severely dehydrated. He was found to have Pyloric Stenosis (PS) and needed surgery. Dr GRO-B at the BCH asked me about my family history and I told him that my Uncle GRO-B was a haemophiliac under the care of Glasgow Royal Infirmary. His daughter is a carrier with a 50% chance of having a haemophiliac son and I asked if I too could be tested. Dr GRO-B intimated to me that he would follow that up in addition to monitoring S's haemophilia levels as he was struggling to get proper levels for him. I had lost my first baby, S was my second born and he was seriously ill. It was a fraught time for me. I was told by Dr GRO-B that S had haemophilia and I accepted what I was told. I trusted the doctors. I assumed that he was following up on the information I had provided about my family history but the carrier test I asked for didn't materialize.

5. S attended at the Haemophilia Centre at BCH for routine appointments several times a year until he was 18 years old. He was under the care of GRO-B GRO-B in the 1980's and Dr Williams from around 1994. His was referred to the Liver Unit at the GRO-B when he turned 18. S and I were sent to Dr Wilde in the Haematology Department at S's first appointment and Dr Wilde told us that S did not have Haemophilia. He was very abrupt and offhand about it. His words were 'You are not a haemophiliac. I don't know what the Children's Hospital were playing at!' We were pretty much dismissed to go back down to the Liver Unit. We were left shocked and angry. I am annoyed with myself that I didn't question Dr Wilde on it further.

6. I believe S to have been treated with FVIII concentrate on just two occasions (as verified by the UKHCDO records he has recently received). The first occasion was when he had the PS operation in late GRO-B The second was when he was being treated for a GRO-B as an outpatient in GRO-B He was treated by Dr GRO-B on both occasions and with Armour Factorate in GRO-B and FVIII BPL in GRO-B After that (in GRO-B GRO-B, S was given a synthetic product (DDAVP) by Dr GRO-B to treat two accidental injuries.

7. My husband GRO-B, and I were not told beforehand about the risk to S of infection from FVIII concentrates. My husband took S to A&E when he broke his collar bone in GRO-B S's misdiagnosis was that of a 'mild' haemophiliac. I must have a sixth sense because I said to my husband not to let them 'treat' S when they left for BCH. Despite my warning about the risk of infection, my husband faced with his child in great pain from his broken collar bone, agreed to them giving S treatment. My husband felt pressurized and it was something he later never forgave himself for. It affected him for the rest of his life.

8. Referring once again to S's UKHCDO records, I understand that S was tested for HIV on 9th January 1987. We knew nothing about it and were unaware of any risk. At that time we still thought that S, a mild haemophiliac rarely needing treatment, would lead a normal, manageable life. I was divorced and moved to GRO-B for work for a short period of time and S was seen at the GRO-B Hospital in GRO-B at the end of GRO-B

9. We were called in to see GRO-B at BCH when we returned to GRO-B in GRO-B as a follow up to a blood test. At that appointment we were told that they had 'discovered something in the blood'. What it was they had discovered was not made clear. I did not want to say too much as S was with me. As they were S's appointments, I was never alone with the doctor and I believe that suited Dr GRO-B I was never taken to one side or offered a one to one appointment out of S's earshot. Everything was always drip fed to me and I had an uneasy feeling at the back of my mind. I remember asking to see S's records but they didn't materialise.

10. At a regular appointment in or around GRO-B, Dr Williams was introduced to us as Dr GRO-B's successor. He told me that S had HCV with possible liver damage. He said that S had a shortened life expectancy and would not live beyond the age of 30. S heard it. It was said in his presence. He was just 14 or 15 years old. I asked to see S's records and I was subsequently told by Dr Williams that he thought they had been lost. As we left the appointment, the Nurse said 'Sue them. Get them'. It was all so odd to

me then. I was left devastated and confused. My Uncle GRO-B had had what I thought was the exact same treatment in Scotland and was living a normal life. He died just last year. No information and/or advice aside from possible liver damage and the bleak prognosis was given to us to help us to understand and manage the infection.

11. As referred to above, just four years later we were abruptly informed by Dr Wilde that S does not have haemophilia and was consequently treated and infected for no reason whatsoever.

Section 3. Other Infections

12. I have recently learned that S, was, much later, informed of the possibility that he was exposed to vCJD.

Section 4. Consent

13. As referred to at paragraph 8, S was tested for infection without consent. I do not know whether or not he was treated for the purposes of research. I refer to paragraph 23 as I often wonder about S's misdiagnosis and the implications of that.

Section 5. Impact of the Infection

14. Beginning as teenager and continuing to the present day, S struggled with fatigue, anxiety, a panic disorder and depression, all as a direct result of the HCV treatment.

15. S had a liver biopsy in GRO-B just after we were told of the haemophilia misdiagnosis and it showed scarring on his liver. He was just GRO-B years old.

16. Being infected with HCV has had a huge impact on S He had his first attempt at clearing the virus in GRO-B This treatment involved injecting himself three times a week for a year. It was stopped after 11 months as it showed no signs of success. The treatment came with huge side effects and he missed a lot of schooling. S lost weight, he fell into depression, his hair started falling out and he had panic attacks. I had to watch him like a hawk, fearing he would fatally harm himself.

17. There was a massive stigma associated with HCV and S's classmates became aware that he was infected with it. The lost schooling affected S's GCSE grades and his career as he was pushed back and did not then go to university until much later in life. The school worked with him to get through his GCSEs but not being able to take part in sport remained a great loss. He found a job he enjoyed in a music store when he left school. We found that even dentists were prejudiced against people with HCV. We had to find a private dentist and they donned full PPE with gloves and masks for the appointments. They didn't really want him as a patient. HCV was associated with drug addicts and prostitution.

18. S has had CBT and counselling for many years. It was funded by us privately. I remember having to contact S's GP whilst we were away in Florence. I had managed to get S on the aeroplane but once there he couldn't come out of his hotel room. I was advised by the GP to buy sedatives (available over the counter in Italy) to treat the panic attack episode and little by little he was able to leave the hotel and, by the end of our stay, get to see Florence. In retrospect I believe S to have suffered with PTSD. At that point his whole life was just miserable and has continued to be very challenging.

19. S was offered a combination treatment of Interferon and Ribavirin at GRO-B many years later in GRO-B This course was for 1 year, which he completed and it successfully cleared the HCV. He had similar side effects to the first attempt at clearing HCV.

20. The impact of this scandal altered our lives forever. We have no trust in the medical profession. I was emotionally unavailable to my daughter as the focus of my attention was S, S was most of the time angry. S is now married with two lovely girls. However I worried for a long time about whether he would be able to find an understanding partner. Equally concerning was the ability to live life normally given the difficulties securing mortgage, life insurance or any insurance for that matter. My parents are gone now but they were devastated. They trusted the NHS and didn't understand. My husband struggled for the rest of his life and became GRO-B dependent. He died as a result of this in GRO-B aged GRO-B

Section 6. Treatment/care/support

21. We faced difficulties getting the first Interferon treatment. In the mid GRO-B when S was diagnosed we were told by the doctors that there was no cure but then they said there was a wonder drug, which was being used in the USA. However, the NHS would not fund the treatment and they suggested that we should consider funding it privately. It was clear there was treatment available and it should have been offered to him. It was subsequently provided as a trial at BCH in 1996.

Section 7. Financial Assistance

22. I rely on S's Statement in this regard.

Section 8. Other Issues

23. When S was just 6 weeks old and seriously ill, I told Dr GRO-D that my Uncle GRO-B was my mother's brother. It is, of course, highly unusual for haemophilia to be passed down the female line across 3 generations. For S to have

haemophilia it would have been passed down through my grandmother to my mother, through me to S I always queried in the back of my mind how it could have happened. I would now like to know why Dr GRO-D took that route and made the haemophilia diagnosis when he did.

Anonymity, disclosure and redaction

24. I confirm that I wish to apply for anonymity.

25. I do not wish to give oral evidence.

Statement of Truth

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

Signed... GRO-B

Dated 21 October 2020