Witness Name: GRO-B
Statement No: WITN1152001
Exhibits: 0
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B of GRO-B I was born on GRO-B I am GRO-B years old, I am currently living with my husband, and I am retired as my health was severely affected by grief and the stress of my own health conditions. I was working in GRO-B and I really enjoyed the job. I have a daughter who lives in GRO-B.

2. I make this statement in relation to GRO-B: S, my late son who was born on GRO-B and passed away on GRO-B

3. This witness statement has been prepared without the benefit of access to my late son's full medical records.

Section 2. How infected

4. My son suffered from moderate Haemophilia A. He was born prematurely due six weeks later so the hospital had to run various tests on him to ensure nothing was wrong. I had suspected that S may suffer from Haemophilia as my father and his

brother were both Haemophiliacs. However, I received a letter in the post to say that nothing was wrong with him. As a child S would get horrendous lumps on his head and we would have to take him to the hospital every time. I would ask the staff if they were sure that he did not have Haemophilia. They always replied that nothing was wrong with him. When he turned three, S banged his knee. At first we called our GP who examined him at home and referred him to the hospital for X-rays. I asked the doctor if my son had Haemophilia to which the doctor said, "Do not be silly." They referred him on to another hospital as they believed he had an aspirated knee. This was extremely distressing, not only for my son, but for us parents and his sister. S screamed in pain because the medical staff had to physically pin him down. Again, I asked the doctor if they were sure he did not have Haemophilia to which he replied, "No." Nevertheless they referred him for the tests. Once carried out the results were sent to my GP, however I was kept waiting. Only when I asked did she confirm his diagnosis.

5. My GRO-B had two sons who suffered from Haemophilia were treated in Manchester so she recommended I go there for my son's treatment. I was told by the hospital in Manchester that I was better off remaining with the hospital in Liverpool and from then, my son was treated at Alderhey Children's Hospital. He would go in for treatment whenever I noticed a signs of bleeding. It was here that he received treatment for bleeds. After his initial diagnosis he was treated with Cryoprecipitate, but if the hospital was low on stock, they would contact the Royal Liverpool University Hospital who would provide them with blood products including Factor VIII treatment. I cannot say for certain when he first received Factor VIII treatment, however I do believe that it was administered from a very young age. In particular, in late 1984 my son had a knee bleed and had to have a lot of Factor VIII so I strongly suspect it was that batch that caused the infections. I was never informed that they were changing the products, and no conversation informing me about the potential risks of Factor VIII took place.

6. When my son was eleven, I received a letter in the post disclosing that my son had been infected with HIV which they had attributed to Factor VIII treatment. We did not know what HIV was at the time so we were asked to attend a meeting at Alderhey alongside other parents whose children were infected in the same way. At the

meeting there were approximately fourteen families. I would have preferred a one to one meeting and I felt calling all the infected persons families together was very unprofessional. The doctor chairing the meeting was a consultant Haematologist. They told us that a batch of Factor VIII treatment has been contaminated. The only advice we received at this meeting was to be careful around our son's blood.

7. I was an active member of the Haemophilia Society who would often hold meetings and it was through this that we found out more information on HIV. Dr Hayes from Manchester spoke at one meeting and said that family members of infected persons should have been getting regular check ups. I had no such check up as none had ever been offered to me, my husband or my daughter.

8. My son was also infected with Hepatitis B and Hepatitis C. We were told by Dr GRO-D GRO-D sometime between 1990 and 1991 at a clinical appointment. Prior to this we did not know that he had been tested. When he went to the clinic he would get a blood test done every time, but we never knew what they would test his blood for. Dr GRO-D told us that both the infections were active and that he was infected because of contaminated Factor VIII. I cannot recall any advice or information being given to us of the risks of transmission or how to manage or cope with the virus.

Section 3. Other Infections

9. As far as I am aware, my son was only infected with Hepatitis B, Hepatitis C and HIV.

Section 4. Consent

10. When my son was diagnosed with his conditions he was underage and so I would have provided consent to his treatments. I do believe that my son was treated and tested for HIV and Hepatitis C without either of our knowledge, consent and without being given adequate or full information.

Section 5. Impact of the Infection

11. My son was only twelve when I told him that he was infected with HIV, although we had kept him in the dark for eighteen months. It was a very difficult time for him, especially given the stigma. Like us, he didn't understand what HIV was and he went very silent. It was the hardest day of our lives. He would try to brush off the truth as he did not want to upset us. We tried our best not to upset him. Due to the stigma, he could never tell his friends about the HIV, although he did tell them that he had Hepatitis C, and to this date they believe that was the sole cause of his death.

12. My son was a lovely and lively boy who was always very active and outgoing. He would want to participate in sports but he couldn't do much. He preferred playing outside with his friends to staying indoors and reading books. As he grew older, particularly after he went on medication for HIV (AZT), he started becoming less sociable and wanted to stay at home all the time. The AZT caused him terrible pains, headaches and severe diarrhoea. Also, my son did not like me going far away from him. He would become anxious and upset whenever we were apart. He also lost his appetite and a lot of weight. We would try to take him out and would go for visits to the pub for a meal, but he would often refuse to eat. The AZT also caused him to get thrushes in his mouth and tongue, night sweats, vomiting, mood swings and depression.

13. Because of his bleeds he could not work. He wanted to be a painter and decorator and even went to the college to do a course, but on his first day they had him on his knees painting skirting boards and he had a bleed so he could not pursue this career any further.

14. In GRO-B, a couple of months prior to his death, I got a feeling that my son would not have long left. We had just come back from a weekend away but all throughout the journey he had been sick. On our return journey he did not look well at all and got a very high temperature. He said to me that he thought he was going to die. I said, 'don't be daft' and he said again, 'I really do feel like I am going to die.' I telephoned GRO-B, our nurse, who told us to take him to the hospital. They gave him antibiotics and discharged him as my son did not want to stay in overnight. In

September 1996, I spoke with my boss and told her I would need to leave work. I did everything I could for my son. My daughter who was pregnant also helped out a lot. We brought him a mobile phone (which was rare during those days) in order to ensure that we were always able to contact him.

15. In October 1996 we had a couple of family occasions to attend to. One of S friends was having a child and my son asked him when the baby was due. My son said he would not be around then. He felt he was going to die although I do not believe that he was ever given a life expectancy. There was only one clinical appointment that he attended which I did not attend, I do not know if he found out something then which I do not know.

16. Three days prior to his death, S mind was affected and he was unable to remember things. He was getting his words mixed up. He had committed to taking his friend and two children she knew to the cinema and I tried to convince him not to go. He insisted that he did not want to let them down so I dropped him off and picked him up. When we got home, he had a bath and I made him a hot drink. He ate a lot on his return home and I remember thinking that he had become so skinny, but I was glad his appetite was better than normal. He went upstairs to sleep, but struggled to do so. He asked me to phone GRO-B and she asked me if she could talk to him. GRO-B asked him if he would prefer coming to hospital or staying at home. He said he wanted to go to hospital and GRO-B met him there an hour later.

17. We took him to hospital eventually where they got him into a bed and gave him morphine. I had planned on staying all night, but the staff convinced me to go home. I could not sleep and the next morning I returned. He was in terrible pain and I knew that he would not be leaving the hospital alive. They had stopped all his medication and said they would try to make him as comfortable as possible. I stayed with him for three days until he passed away in my arms. His father was also there that day.

18. He was never offered any treatment for his Hepatitis C virus. It was mentioned when he was told he had the infection that there was Interferon treatment available, but my son was informed that he was not viable for that.

19. In terms of my son's dental care, he would not to get any treatment at the hospital's dental department and would have to wait until the last appointment of the day. We would always be kept waiting for ages and when they were ready for us; the dentists came in dressed in full body suits. I joked that they looked like spaceman to make light of an intimidating and frightful experience. When he had to get treatment the porters would refuse take him to the operation theatre which was very upsetting for him.

20. My daughter has five children and two of her sons have Haemophilia. The older of the two was traumatised to hear what happened to S He thought he would die as well and GRO-B had to sit him down and explain everything to him. My daughter always felt that her brother could have married and had his own children and she was always bitter about what happened to S.

21. My GRO-B lost her daughter two years before S passed away due to learning difficulties which was awful, but it was not the same as S My sister did not understand that. I did not want to tell my mother as my father died in 1986, so my mother was on her own. My father in law used to get so upset whenever we spoke about S He always said, "Why could it not be me?" The effect on the whole family was devastating.

Section 6. Treatment/care/support

22. No support was offered immediately follow my son's death, despite the fact that they had committed that terrible crime. It was five years later that The MacFarlane Trust set up bereavement weekends which really helped. We were put in groups with other parents who had gone through similar experiences which made it very easy to talk to each other.

23. S had a social worker who would sometimes provide him with assistance, but rarely actually did. Personally, GRO- used to counsel me. I found it very beneficial as I could say everything that was on my mind and got all my anger out. On the other hand, my husband had no one.

Section 7. Financial Assistance

24. S received monthly payments of £800 from the MacFarlane Trust until he passed away. In 1990 he received a lump sum of £20,000 which was put in our bank account as he was underage. In summer 1991, he was awarded another £25,000 had to go in a trust as he was still underage but it was paid to him in December of that year. He used this money to enjoy what life he had left. He loved us going on holiday and treasured those memories

25. After S passed away, I received £1,000 towards his funeral costs from the MFT.

26. S received nothing from the Skipton Fund. I applied and received the Stage 1 payment of £20,000 and Stage 2 payment of £50,000.

Section 8. Other Issues

27. I was an active member of the Haemophilia Society and I have been involved in raising money for Alderhey Hospital.

Anonymity, disclosure and redaction

28. I confirm that I wish to apply for anonymity. I understand this statement will be published and disclosed as part of the Inquiry.

29. I do not wish 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

Dated 26-4-2019