Witness Name: GRO-B
Statement No: WITN7467001
Exhibits: 0
Dated: December 2022

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 I reside at GRO-B GRO-B My date of birth is GRO-B. I am divorced and live alone. I have 2 children and I am now retired.

2. This witness statement has been prepared without the benefit of access to my Son GRO-B:S s full medical records. We requested them for an earlier Inquiry and when S left home, he took them with him, so I do not have access to his records, but he does have them and he has provided a statement to the Inquiry under reference GRO-B

Section 2. How Affected

3. My son S was infected as a result of the treatment he was given for his haemophilia. He has Haemophilia A which is severe and would bleed regularly. He was 5 months old when he was diagnosed and treatment started. He is now 42.

4. As far as I can remember S was treated with Armour Factor 8 and Cryoprecipitate. He only had Armour Factor 8 as far as I can remember.

5. We were told that S needed to be tested for the viruses and he was negative, but then in 1984 we were contacted and told we had to take the treatment we had at home back to the hospital and couldn't treat him at home anymore and that he had to be treated in hospital going forward. He was given cryoprecipitate and we were then pulled into a meeting and were told that Armour had confirmed they had a process of heat treating the Factor 8 and he would be given the heat treated product and they promised there would be no HIV infection in the product, although they said they could not guarantee the hepatitis situation. He was then put on that.

6. When he was 4 years old, he contracted Hepatitis B but naturally cleared the virus.

7. When he was 6 we had to take him to hospital for a bleed as we could treat at home but if it didn't settle we had to take him to the hospital which we had to do on this occasion. Sister Marion said that she had to have a word with me and pulled me to one side and said they had had a batch of the Armour Factor 8 that had been flagged as having a problem and that they would have to test S for the HIV infection, there were another 3 or 4 lads in our unit in the same position and had to be tested. This would have been sometime in around August of 1986 when S was 6 years old, and then in January of 1987, after Christmas I received a phone call one evening around tea-time from Dr Hill, the consultant, who asked was I on my own. I told him no I had the children with me. He asked when my husband was due home and I told him not for an hour or so as he was at work, and he then said that he was sorry to have to tell me that my son has converted and is HIV positive. I couldn't speak when he told me this, he asked whether I was ok and I said no not really. I can remember the conversation as if I was having it yesterday. He asked would I be ok and I said I didn't know, I just said thank you very much and put the phone down. I just went into the kitchen and the garden and fell apart.

8. I spoke to my sister, my Nephew, GRO-B had converted in 1984 so I knew about it and I knew other children from our unit and their families. When I was at the hospital some time later I was left in a room with S 's file open on the table and I was able to read that his conversion was 19th November 1986, GRO-B GRO-B. They did not tell us until the January so they had known for a couple of months and not told us.

9. S was treated at Birmingham Children's Hospital. Initially when he was diagnosed, he had had a brain haemorrhage when he was 5 months old and due to the way he was reacting to everything they confirmed he had haemophilia. Before his diagnosis I had been convinced they were going to tell me he had leukaemia. When he was diagnosed, I was told there was no reason why he could not live a long normal life. It was when we were transferred to the children's hospital that I met sister Marion and she told me what would happen with treatment. She told me the treatment they had now was revolutionary and she told me that S wouldn't suffer like the older men who had had nothing but plasma to be treated with and were affected by rheumatoid arthritis, she told me this wouldn't happen to S I was relieved to hear that and I had to learn about haemophilia and learn how to live at home with him and how I would have to take him to hospital when I thought he was having an internal bleed. It was very stressful not knowing at 5 months old if he cried was something wrong or not.

10. Although the diagnosis was a shock it was also a relief it was not leukaemia.

11. It was very difficult and stressful as he was so young, he was 5 months old and when he cried I didn't know whether there was something wrong haemophilia wise or something else. Once we had started on the treatment we were told there was a chance he could contract hepatitis but nothing more was said about it then and we didn't know about it.

12. When my son was diagnosed, they asked about the family and whether anyone was affected, we didn't know, my sister had 2 boys so she had them tested, one was ok but the other one was diagnosed with haemophilia, so we were kind of in it together learning about this new thing.

13. We ended up forming a little group with some of the other mums who had boys with haemophilia and did little fundraising things to raise money for the haemophilia unit, we became our own little support team. We were assigned a social worker named GRO-D although she never knew a lot, but she would be there if there were meetings. The hospital would have a kiddies party at Christmas and she would also attend that. We would hear horror stories from some of the mothers about haemophilia so I then decided not to go as much, I didn't want to know what was coming down the line. We would still carry on using the hospital, then there would be incidents where he would have to stay in hospital for various bleeds and my nephew was the same. We then learnt how to do the Factor 8 injections at home. I was nervous to do this but learnt how do to it. I also learnt how to drive so I didn't have to rely on ambulances to take us to the hospital when he had a bleed as we would sometimes have to go 2 or 3 times to get a bleed under control so it was easier if I could drive.

14. S was infected with HIV, Hepatitis B and Hepatitis C. He naturally cleared the hepatitis B when he was very young and naturally cleared the Hepatitis C when he was around 18 or 19. He has also suffered from B cell lymphoma cancer and we believe this is related to the Hepatitis C infection. We then got a letter from the hospital saying that S had had treatment donated by a man who had gone on to die from vCJD and so he was at risk of that. I was so angry at that point we knew there was treatment with artificial Factor 8 that was produced and being used and we asked if he could go onto it but we were refused they told us there was not enough funding and they were giving it to boys who had been newly diagnosed with haemophilia. I remember thinking it wasn't right and went to my MP but he said he couldn't help then we had a letter to say they were making more and they would give it to everyone.

15. I remember we were told not to tell anyone that S was infected, even if it came to his schooling. We were told it was up to us, but they advised with people's attitudes it was best not to tell anyone as the infection was new and they were still finding out more and more about it and how it affects people. They never really sat us down and told us this is what is going to happen, there was no

treatment at that time in the early days. I was fearful, I thought he was going to die, but I tried to carry on with life as normal. My own conscience would not let me not tell the school, so I prepared myself for the worst and had a meeting with the headmistress and told her. She said she would have a meeting with the teachers because of the fear connected with the infection so she told them what had happened as well to allay their fears and told them to ring the hospital and speak to Sister Marion with any concerns. I also had leaflets I gave to them. I wanted them to keep it amongst the staff and not let other mums know.

16. I felt guilty for not wanting the other mums to know, but there were safe ways they could treat S and I felt he would be safe and not a danger to anyone, as long as they didn't touch his blood and used the protective gloves and disposal bin which I supplied for them. The school were very good and kept it confidential.

17. I used to tell very close friends, I still have those friends today. I have been lucky. I know of horror stories of children not being allowed to go to school and their friends no longer being their friends, so in that respect we were lucky.

18. We had the same when he moved to senior school and they were ok there too. When he was 10 he had a epileptic fit and weird things were happening which we couldn't understand until he was diagnosed with epilepsy. The epilepsy was due to pressure in the brain, that in itself was another issue, and was a bit scary. S would have a fit but carry on walking, so he would be in an unconscious state but still walking. He had an experience where he walked to a neighbours in this state but they knew he was not well so brought him home. He had that for around 10 years and then it went as soon as it came. It did cause issues with his haemophilia and his HIV because he could bite his tongue or fall over so I practically lived at the school. I was frightened to go anywhere until I got a pager.

19. We had total trust in the doctors and nurses, we considered they knew what they were doing and would tell us what we needed to know when we needed to know it.

20. Because I had my sister to speak to we knew more or less what was going on and what it meant, her son had contracted HIV before S so I could talk to her about it. Basically, all we really got told was to follow all the procedures and wear gloves and wipe surfaces down with a sterile cleaner and to use a burns bin. We were told we could still drink out of the same cups and sit on the same toilet, all the fears that the public had what with all the rumours about the infection that went around at that time. We were told we could kiss him, put our hands on him and love him as our child, it was all safe, we just needed to be careful with blood, wound on wounds and if we pricked ourselves with a needle so we had to be careful.

Section 3. Other Infections

21. I am not aware of any other infections other than HIV, Hepatitis B and Hepatitis C.

Section 4. Consent

22. Tests were done on the children in 1984 and the majority of the kids tested were infected, I only know of S who wasn't at that time. I am not sure if he was ever tested without my knowledge or consent.

Section 5. Impact of the Infection

23. My son is a marvel on legs really, he just took everything that was thrown at him and got on with it, especially as a child. He didn't really understand at a young age, but we told him if he cut himself at school the teachers needed gloves on to help him and that he needed to remind them. He never really complained about anything he just got on with it.

24. Mentally it was always there on my mind, were we going to have him for long, would something go wrong with his health. It did have an effect on my marriage. I was dealing with all the issues around our son's diagnosis. I felt my husband tried to be supportive and did his best but mainly it fell on my shoulders as he

was at work trying to keep his job. If our son was in hospital I would try and arrange for him to collect our daughter from school if he could, but we couldn't be normal with the children, he couldn't have the normal rough and tumble other kids would have, our marriage broke down in the end, we had been married for 27 years and together for 30 years, it had been hard for a long time.

25. We were not really living in a normal situation and my husband turned to drink. Our life revolved around S even holidays we would have to think where we could take him what was suitable, was there a Haemophilia centre close by. We never socialised much, S had some little friends, but he never had many friends. GRO-B, my nephew was a big friend to him and when we lost him it was a big thing. He also had another little friend who used to come round, he had a disability and they became friends at junior school. S had a very small existence really as a child.

26. One of my most difficult memories is when S was a young teenager, I was told by the hospital that I should tell him that he shouldn't have children because of his HIV. This was devastating for both of us and S never spoke about it with me again. The idea of not being a grandmother by him was heartbreaking and is indicative of how much S's illness has taken from us.

27. S continues to suffer with his health as a consequence of the infections. He has cleared the cancer but the damage to his health is ongoing.

Section 6. Treatment/care/support

28. We were told to stay with the hospital dentist, so when S was 7 he had teeth coming above the gum line so he needed to have that sorted out. Before we went into our appointment, they called every other person before us, when the last person had gone they came out and told us they would call us in a minute. We were called in and I was dumbstruck. Every section of the room had been clingfilmed, everything was clingfilmed it was like we were a bio hazard. It looked so scary, it was bad enough having to take him to the dentist anyway.

That went on for a bit and then I and other mums complained. It was sort of sorted out, it was not as bad, they then just used protective stuff on themselves.

29. S has suffered with mental health side effects from the infections. He had a problem when he was around 19 or 20, he pretty much lived in his bedroom. He never came downstairs and didn't go out. He just didn't interact with people. He tried to get into college but he was showing signs mentally of not being ok. I rang the hospital and spoke to a social worker, they came to the house a few times. Basically S didn't want to grow up, he didn't want to be an adult in an adults world. He eventually got into a college across the road from where we lived and did art. He was doing ok, but it didn't work out in the long term, it wasn't what he wanted to do, he didn't attend for long and he retreated to his bedroom. My husband got him into snooker so he would go and play and he eventually met a girl.

30. As far as I am aware he has not had counselling. We were never offered any when he was a child. I have always tried to be strong, to carry on. When I was divorcing it all became too much and my GP gave me some medication but I only took it for a short period.

31. I never experienced any stigma associated with the infections, we were just told you cannot tell anyone,

32. S s infections have had a big impact on our family.

Section 7. Financial Assistance

33. The McFarlane Trust said they would pay for a holiday for us, we didn't ask for it, they just told us this, but we said no that we would pay for our own holiday. I do not remember being given anything else. I recall we had letters saying we could get blankets and bedding but we didn't claim for these we thought there were people in a worse position who needed them more.

34. S did get some money from the government, I think it was around £22,000.

Section 8. Other Issues

35. The Inquiry needs to find out what went wrong. Someone did this to my son, and to other children. They did say at some point they had a laboratory and needed funding to produce our own Factor VIII so we would not need to buy it from America, knowing how it was sourced there, but nothing ever came of that and I don't know why.

Anonymity

36. I wish to remain anonymous.

37. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed. GRO-B ....

Dated 12.12.22