Witness Name: GRO-B
Statement No: WITN1292001
Exhibits: 0
Dated: February 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 I was born on GRO-B and I am GRO-B years old. I live with my husband GRO-B at GRO-B GRO-B

2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006. I am aware that my husband GRO-B will also be giving a statement.

3. My late son GRO-B: S was born on GRO-B and sadly passed away on GRO-B as a result of being infected with the human immunodeficiency virus (HIV).

4. This witness statement has been prepared without the benefit of access to my son's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

5. My son, S who was born on GRO-B, sadly died from HIV as a result of receiving contaminated Factor VIII for his Haemophilia.

6. When S was around 6 months old, we noticed that he bruised very easily, so my husband took him to see our GP. The GP examined S and he was concerned that he was being abused at home. We were adamant that this was not the case. S was eventually referred to GRO-B General Hospital; he was tested and diagnosed with severe Haemophilia A at the age of 18 months.

7. S was initially treated with fresh frozen plasma at GRO-B General Hospital. In or around 1972, when S was about 7 years old, we were advised that he could be treated with Factor VIII at the Manchester Royal Infirmary. We were told this treatment would mean a better quality of life for S because he would not have to stay in hospital overnight when he had a bleed. We decided to follow this advice and S began treatment with Factor VIII. I was not given any further information on the Factor VIII nor was I advised of any of the risks associated with taking blood products.

8. In or around 1975, when S was around 10 years old, we were told that he was being treated with heat-treated Factor VIII. In around 1977, my husband was trained on how to administer S's treatment at home and he began doing so regularly.

9. Due to S's Haemophilia, he had missed a lot of school. As such, we decided to enrol him at Treloar's School when he was 11 years old. I cannot recall how this came about, but I believe we were advised to do so by a counsellor at the educational centre, because he would need a good education to find a job that did not require manual work. Whilst attending

Treloar's School, S s treatment was administered by the staff whenever he had a bleed.

10. When S was slightly older, we were advised that S was doing really well and that he was healthy except for his Haemophilia. However, when he reached his early 20s, in the latter half of the 1980s, we were called to attend Manchester Royal Infirmary with S as an emergency. We were told to take a seat and the doctor informed us that S had been infected with HIV. We were stunned, but we were told that he might not get AIDS because of all of the research that had been done. We were all very confused as we were not expecting this kind of news

11. We were later advised that S had contracted HIV because he had received contaminated blood that came from America. We asked how this was possible because we had been told that the blood had been heat-treated, but we were not given an answer. We were merely advised that he had been treated by contaminated Factor VIII that came in to the UK sometime in or around 1983.

12. S was not provided with any information on how to manage or understand his infection. He was told that there is not much that can be done for him in this situation.

13. A few years later, we were informed that S had also contracted Hepatitis B and C. This information came out in a casual conversation with the nurses, at a routine appointment. At this point, S had already developed AIDS, so this was the last thing he needed to hear. I did not know anything about Hepatitis, so when the doctor told us it was an infection affecting his liver, I could not believe it. S did not receive much information from anybody about either of these infections and his doctor gave the impression that this was not a serious illness.

Section 3. Other Infections

14. I am unaware of any other infections that S may have contracted as a result of receiving contaminated blood products.

Section4. Consent

15. S regularly underwent blood tests, which we believed were for his Hemophilia. We were unaware that S was being tested for any infections. As such, I consider that he was tested without our knowledge or consent.

Section 5. Impact of the Infection

16. When S was diagnosed with HIV, he became very depressed. We were very concerned about this and even thought he would try to take his own life, which was a scary thought because he was regularly doing his own injections so could have done anything.

17. His infection had a big effect on his mental health. His attitude completely changed and he kept to his bedroom. He did not want to go out or spend time with friends; he was not the same boy he had been before.

18. Prior to being informed of his HIV status, S had a girlfriend but when we found out he had to tell her and she was required to get tested as well. She was stunned when she found out and did not know how to react. Fortunately, she was not infected and they remained together for a while. However, she did not realise how serious it was until the later years, S s health started deteriorating rapidly and he was too unfit to spend quality time with her. Their relationship eventually came to an end and this was a difficult time for both of them. After this, S did not want to be in another relationship.

19. [redacted]s physical health was also affected by his infection, especially when it developed into full-blown AIDS. He lost a great deal of weight and he had no meat on his bones, you could really see this on his face which had gone right in and became sallow. He struggled to eat due to pain from the terrible thrush in his mouth, so he had to eat liquid food that we would prepare for him beforehand. My husband and I wanted to feed him a lot, but even if we did, it did not make a difference to his weight as he was wasting away.

20. [redacted] underwent treatment with AZT and other antiretroviral drugs. This treatment was toxic and he experienced a lot of pain around his stomach, which we now believe was due to the condition of his liver. When he walked he held his stomach because the pain was so bad. It was heart-breaking seeing him in so much pain.

21. He experienced terrible side effects from the treatment, which mostly affected him at night. He slept very badly and would shout out in his sleep and cry. He would wake up and be sick a lot, and we would often hear him vomiting in the bathroom. This affected us at night and we kept our door open to listen for him, in case he needed our help. This happened every night for five to six years.

22. [redacted] did not face any difficulties obtaining treatment. There were always new treatments and medications available and whenever one came out they offered it to him.

23. [redacted] did not have a social or private life after he was diagnosed. He used to enjoy fishing and loved wildlife. He had a lot of friends prior to his infection. However, the stigma ruined his friendships. He did not tell his friends about his infection, but people knew he had Haemophilia and everything in the media was talking about the two in connection with one another, so people started to guess. We stopped all of our friends coming to our house and in the end [redacted] only had two friends left.

24. Due to the stigma associated with HIV, we became very lonely and isolated and lost all of our friends that we had for around forty years. How do you sit down and tell your friends, when people are saying that victims of HIV and AIDS should be shot. It was a very difficult, lonely time for us and it would have helped if we knew people that were in the same position as us. Although we saw a few people regularly at the clinic, we did not know them very well.

25. We did not even tell our family until the last minute, towards the very end of S's life. They were shocked that we did not tell them, but when we explained that S did not want people to know they understood.

26. After S developed AIDS it was such a busy time for us and it was like working a 24-hour day shift, every single day. It affected every part of our lives, even down to planning what food he could eat that would not hurt him. We also had to be very careful at home and sterilise everything. My husband and I were his only carers and we could not make any arrangements to go anywhere or do anything, so we would have to wait until the day before and see if we could manage.

27. During this time, I continued to work part-time and my husband had retired due to an injury. I worked for social services and would do home visits and planning packages of care for people. I would have liked to progress at work and go into a management position, but at the back of my mind I was aware that I did not know what would be required of me to look after S later on.

28. My husband and I have been trying to put this behind us, but we will never get over what happened to S. If we hear a sound in the house at night, we think we are listening out for S and sometimes catch ourselves thinking that he is there. We still have days when we break down over S's death. It is especially upsetting when people talk about their children or grandchildren, because we have nothing at all.

29. S loved Christmas, but since he passed away we have not been brave enough to celebrate it so we do not put up any decorations or celebrate the day at all.

30. Even though S passed away twenty-six years ago, we kept his bedroom exactly the same until three years ago. Every time we walked in we felt devastated and eventually we realized that we needed to change it. We also destroyed any documentation relating to S s condition or his infections. This was the only way we could try and move on.

Section 6. Treatment/care/support

31. S and I received counselling from an AIDS counsellor who approached us whilst we were on a routine visit to Manchester Royal Infirmary. My husband could not face it, but S and I both accepted the support. For the last eighteen months of S s life, she came to our home for counselling sessions.

32. When S passed away the counsellor continued coming to see me for approximately twelve months.

33. My husband was later asked to attend counselling, but had a negative experience with the counsellor.

Section 7. Financial Assistance

34. When we cared for S we received an attendance allowance but I cannot recall how much we received. This payment stopped when he turned 18.

35. S received a payment of £2000 to change his bedroom and make it more comfortable, because he was going to be spending all of his time in there. I believe this was from the Haemophilia Society, but I cannot recall

what year it was. He applied for this financial assistance himself and we were unaware he was doing it at the time.

36. I believe that S also received a lump sum payment from the government, but I cannot recall how much. He did not really open up to us about the financial assistance and we respected his privacy with this matter.

37. When S passed away, we received some financial assistance for his funeral; I believe this was from the Haemophilia Society. We received a phone call and we were asked if we would accept financial help, at the time our minds were spinning and we did not know what to do. We accepted the assistance and received around £2000 towards the funeral costs.

Anonymity, disclosure and redaction

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

Statement of Truth

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

Signed. GRO-B ....

Dated...18.2.19.............................