

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN7446001

Exhibits: 0

Dated: November 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 live with my partner and I have an adult son.

2. This witness statement has been prepared without the benefit of access to my son, GRO-B: S's full medical records as some of his records are missing.

Section 2. How Affected

3. My son, S had Haemophilia A and was a severe haemophiliac. He was diagnosed when he was under 1 year old.
4. We found out about S's haemophilia because my sister's son GRO-B: N had had to go to hospital. He had had a brain bleed and they discovered this was because he had haemophilia. No one else in the family had it so my 2 sons had to be tested. GRO-B was fine he did not have it, but S did.

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5. [S] was treated with cryoprecipitate at first and then his treatment was changed to Factor VIII, he was given a brand made in the USA by Armour.
6. [S] was treated at Birmingham Children's Hospital.
7. The time period in which he would have been given infected Factor VIII would have been 1983-1984. He was circumcised and had to stay in hospital for a while and was given a lot of Factor VIII every day, I presume this was when he was infected, but I do not know for sure.
8. I was not given any advice or information about any risks involved in the treatment [S] was being given. I didn't really know what haemophilia was at first, it was the first we had heard of it, we had never had it in the family to our knowledge and couldn't trace back as mum's mum died when she was 7 so we couldn't go back further than my sister and brother and he didn't have it. We were told it could have been caused by a mutation.
9. We were still really learning how to cope with the haemophilia diagnosis, trying to find out what [S] could and couldn't do. We wrapped him in cotton wool for a while but we did not want that to continue and wanted him to have a normal childhood. For instance, he had a helmet made so that he could still ride his bike. We were just coming to terms with this and then we got told about his infection.
10. [S] was infected with HIV. My reaction was well what is that then, I didn't know anything about it. I don't know if [S] also had hepatitis, and wouldn't know if he cleared it, some of his files went missing when I sent for them. A lot of the mums of infected children found their files went missing.
11. I was told of [S]'s infection on the ward, I was up there a lot with [S] with his bleeds, we were with Sister [GRO-D] and Dr Hill and were told [S] had HIV. I had to ask what it meant as I didn't know what it was. I was told it could develop into AIDS. I wasn't really listening; I was in shock so couldn't take it all in. I remember they said to tell him he couldn't have children. You can't just sit a child down at that young age and tell them they can't have children. The children didn't understand at that young age. As time went on, I understood

that I had to tell [S] about his infection, and I remember when he was 11 we had a conversation and I told him that he had to be really careful around girls. I don't think [S] understood what this meant at the time.

12. I was not provided with much information when [S] was diagnosed. I was just told that it was from America and we didn't know much about it, I don't think they really knew themselves. I knew [S] had a blood test which came back positive. It was all up in the air really as I never really understood it. I asked where he had got it from and was told it was the Factor VIII, from Armour.

13. We were not provided with adequate information, we were literally just told, that's it they had done their bit. We then had to go home and do our own research. We spoke with the other mums and things, that's how we found things out by speaking to the mums of other infected children. The hospital were no help at all really.

14. It was so long ago that I was told of [S]'s infection now that it is pushed to the back of my mind. I do not remember being sat down properly and informed of the infection, they tried to tell us a few things, but they didn't know much themselves. We had meetings with the other mums, went out for meals as a group and helped ourselves really.

Section 3. Other Infections

15. I think [S] also contracted Hepatitis.

Section 4. Consent

16. I am not sure whether [S] was ever treated without my knowledge or consent. [S] was in hospital a lot and they did do blood tests when I was not there if it was early in the morning. I do not know whether these blood tests were carried out without his consent.

Section 5. Impact of the Infection

17. [S] developed rashes on his body, over his face, arms and back. He also had coughs and colds and we had to be careful with him, his breathing was heavy at times, we would wonder whenever he got a cold was this it, you know, was this the one that would kill him. We didn't really know what to think, we were on a knife edge all of the time with it. It was a constant source of anxiety.
18. [S] was young when he died, he was 12 but I think it did still affect him mentally. [S] did have some friends who he would go out and play with. However, the parents of some of his friends knocked on my door telling me that they did not want their children to play with [S] anymore. After this, he would choose to stay in his bedroom and play with Lego and draw either by himself or with his friend. He did understand a bit about his infection and was clingy towards me.
19. [S] had coughs and sniffles, his breathing was not good and we noticed he was not eating as well as he used to so we took him to the hospital on the 2nd of January I think it was. We took him in as he was not eating and he developed pneumonia while he was in there. He had chest x-rays and was given antibiotics, but it was no good, he died on [GRO-B] 1993.
20. He had been given AZT medication and antibiotics, but it didn't help [S] was not able to be fed intravenously as he kept bringing this back up so they decided to give him a small operation to fit it in. He was also given morphine around this time until he died.
21. We had difficulties with [S]'s dentist. He saw the dentist at the hospital and we were always left until last, even if we had a morning appointment we would be left sitting there all day until the end and when we went in literally everything in the room was wrapped in clingfilm, it was awful, I found it horrendous that they clingfilmed everything.

22. My sister was going through it all with her son as well, he was infected as well and so we just supported each other. [S] was alright at school, because of the bleeds and things in the Junior part of the school when he went in his wheelchair, they wouldn't let him go into the dinner hall they said he was a fire hazard so he wasn't able to use his wheelchair there. The Secondary school was a bit better for him, the teachers understood a bit more. He did alright at school, he was quite clever. He could draw, he was a nice little drawer. When he was at Secondary school, I was given an alarm from the hospital which [S]'s school could use to get in touch. Although it was beneficial as I could always be contacted when [S] was unwell, it became disruptive to my everyday life.

23. I was divorced in 1984 so coped with all of this on my own. Coping on my own was very tough, I was mentally exhausted and would suffer from mental breakdowns which once left me in bed for two weeks. I remember that the doctor came round once when my Mum was staying with me and prescribed me some non-addictive medication to help me. I think I was suffering from some form of depression at the time.

Section 6. Treatment/care/support

24. No counselling or psychological support has ever been offered. We did have a social worker for things if we needed her. We could talk to her but she didn't really know much about it either, so we had to find out ourselves. We didn't call on her very much and tried to cope as a family but we knew she was there.

Section 7. Financial Assistance

25. I can remember the Terrence Higgins Trust and the McFarlane trust. I think the McFarlane Trust gave us a little caravan holiday once but I had no financial support.

Section 8. Other Issues

26. I want accountability for those who are to blame. In my view, the government are to blame as they chose a cheaper treatment which essentially cost millions of people's lives, like [S]s. We also never had an apology from Armour, who have now gone bust. We had £20,000 from the government which I didn't want to accept but we were told that was it and there was no more, it was that or nothing. [S] didn't live for long after getting that payment.

27. When [S] passed away I didn't do very well, I pushed it to the back of my mind, I had another son to look after, [GRO-B] was 15 when [S] died, he was coming up for his mock exams and could not concentrate, he needed a mentor at school for a while to give him a bit of support. [GRO-B] missed [S] deeply and still does.

Anonymity

28. I wish to remain anonymous.

29. 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.....22/12/22.....