

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 the GRO-B and live at GRO-B
GRO-B with my
husband. I am semi-retired and work at GRO-B
2. I make this statement as the mother of GRO-B: S who was born on
the GRO-B and who was infected HIV and Hepatitis C as a result of
receiving contaminated blood products.
3. My son has also provided a Witness Statement to the Inquiry dated May 2019 under
Witness number GRO-B
4. This statement has been prepared without the benefit of access to S's full
medical records.

Section 2. How Affected

5. S has Haemophilia type A, classed as mild. He was diagnosed when he was about
11 years old.

ANONYMOUS

6. I was not initially aware that [S] suffered from Haemophilia. At the time he was diagnosed he was about 11 years old and attending a boarding school in [GRO-B]. The school had taken him to a dentist to have a tooth removed. I'm not sure where this dental practice was. I was told there were difficulties stopping the bleeding after the tooth was removed and as a result [S] spent some time in [GRO-B] near [GRO-B] [GRO-B]. At the time I was separated from [S]'s father, who had suffered brain damage as a result of a heart attack and it was all a bit traumatic.
7. After the incident with [S]'s tooth he began to suffer from regular bleeds. He had gone through his whole childhood without us even knowing that he had Haemophilia. However his symptoms seemed to go from mild to more severe after he had his tooth removed.
8. [S] received Factor VIII blood products for tooth extractions and bleeds at [GRO-B] [GRO-B] until about 1982; the [GRO-B] in [GRO-B] until 1983 [GRO-B] [GRO-B] until 1984 and Worthing Hospital from 1984. He also received treatment at [GRO-B] [GRO-B] in or about 1985.
9. I was not advised beforehand that there was any risk of [S] being exposed to infection from blood products. I was angry that [S] was given Factor VIII concentrate in the first place as I never gave permission for him to receive any blood products. Nobody ever called to ask for my consent and he never should have received it in the first place. They should have informed us. As far as I'm aware my husband at the time wasn't asked for permission and he was not in a fit medical state to give consent.
10. I am not sure when [S] was first infected with HIV and Hepatitis C but I believe it to be in the early 80s.
11. [S] was diagnosed with HIV in 1985/6 he was not made aware that he had also been infected with Hepatitis C until 1996.
12. In or about late 1985 /early 1986 I attended the Haemophilia Centre in [GRO-B] with [S]. I believe it was a routine appointment and we were not prepared for the news we were about to receive. We met with Dr [NOT RELEVANT] who asked [S] to leave the room so that he could talk to me. [S] was around 14 year old at the time.

ANONYMOUS

13. Dr [NOT RELEVANT] then told me that [S] had been infected with the HIV virus through receiving contaminated blood. The news was given in a manner I can only describe as blunt and matter of fact. I remember I was in tears, I was shocked and blindsided by the news. [S] was then asked to come back to the room and was told that he had been infected with HIV, It was very difficult. I thought it was important that [S] was told and I didn't want to hide it from him.
14. Dr [NOT RELEVANT] did not provide us any information that could have proven beneficial. We were told [S] could attend a sexual clinic for any information that he needed. This clinic was at [GRO-B] Hospital. We attended but still did not receive any information to help us understand and manage the infection or the risks of others being infected. The information we were given was clearly not adequate.
15. The news was communicated in a disgusting way. It was so matter of fact and blunt. I was a parent on my own already having to cope with a husband with brain damage, and my only son hitting puberty. They showed no care in the way they told me. The only information I was given was to be more vigilant when he had bleeds.
16. I believe the doctor's were aware that [S] had received infections through contaminated blood a while before they made us aware. They should have told us straight away. [S] was not diagnosed with Hepatitis C until 1996 which is unacceptable. [S] was married by the time he was 17 so he dealt with most of this with his wife by this point but I do not believe they informed him as to when he would have been infected with Hepatitis C.
17. [S] was put on Interferon in order to try and treat his Hepatitis C but it was not successful. He was on Interferon for a year which had horrible side effects.

Section 3. Other Infections.

18. [S] received a letter from the NHS saying there is a possibility that he has also been infected with vCJD through contaminated blood products.

Section 4. Consent.

19. I believe [S] was tested without my knowledge or consent as he was tested for HIV and Hepatitis C when he was a minor. I also believe he was treated without my knowledge

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or consent as again he was a minor when he first received contaminated blood so not in a position to consent himself. I was provided no information as to what risks Factor VIII could present as I was not told [S] would be receiving it in the first place.

20. I am not aware if [S] was tested for the purpose of research.

Section 5. Impact

21 [S] has suffered from many health conditions as a result of his infections. He has had several bouts of pneumonia and collapsed lungs. He has had numerous chest infections and at one point had Tuberculosis (TB). He suffered from diarrhoea and an upset stomach on a regular basis.

22 [S] had to see a psychiatrist to help him to deal with the severe depression he suffered as a result of his being infected with HIV.

23 [S] became very angry, short tempered and had severe mood swings. It was more pronounced as, he had always been a quiet boy. Because he is an only child and his father had such severe medical issues there was nobody other than me to help.

24. When [S] was infected his father and I were in the process of splitting up and his father had suffered substantial brain damage so he was already dealing with a lot. [S] left boarding school and came back to live with me in [GRO-B]. Physically he was okay at first but mentally he was terrible. Before he was infected he had been doing really well at school but he ended up rebelling as a result of his diagnosis. He didn't think he had long to live so there was no motivation for him to do well in school

25 [S] was sent to a school called [GRO-B] for teenagers who needed help because he wouldn't stay in school. He went off the rails which isn't surprising considering what he was dealing with. In the end he stopped going to school, there wasn't much I could do about it, he left school without any qualifications. [S]'s education just came to a halt. He was very good at art and had wanted to become a graphic designer and this went out the window as a result of his infections.

26 [S] then met his girlfriend. I became aware they were possibly sleeping together and he hadn't told her that he had HIV so I had to inform her parents. I felt that it wasn't right that she wasn't aware of the possible risk she was facing. It wasn't an easy thing to do but I

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went and had that conversation which didn't make me very popular at the time. However they are still together and are now married, and have 3 children who are all fit and healthy. I am aware that my granddaughter is a carrier of the Haemophilia gene.

27. I am aware that [S] has been classed as disabled due to his Haemophilia.
28. When [S] was diagnosed with HIV the news of Haemophiliacs being infected with contaminated blood was just hitting the press. A lot of the news would focus on homosexuals or drug users. Therefore it wasn't possible for [S] to talk about the situation for the fear he would have a label attached to him and face social stigma. It was kept a secret so that [S] didn't have to deal with any fallout in his social life in addition to actually dealing with infections.
29. When [S] was first diagnosed with HIV he wasn't offered any treatment at all. When treatments became available he was put on them. I believe he was on Azidothymidine (AZT) for some time.
30. [S] was treated with Interferon for his Hepatitis C the side effects of which were terrible and led to [S] suffering from depression, feeling lethargic and nauseous.
31. I am not aware of [S] facing any difficulties in obtaining treatment or care
32. I believe [S] has been segregated a few times when he has had to spend time in hospital. The reason given was that he could receive infections from other people who were unwell which would be dangerous considering the infections he was already battling.
33. This all had a huge impact on me the whole ordeal has been very traumatic; it turned our lives upside down. It brings me to tears just thinking about what we've been through. I had a fit and healthy young son about to do his exams and embark on a career and it was all destroyed through no fault of our own. He was never the same after he found out he had been infected with HIV and then Hepatitis C
34. I constantly worry about him. It devastated and changed both of our lives. Mentally and emotionally I felt depressed, stressed and anxious. I had to balance dealing with the news myself while also trying to understand how [S] was feeling at the same time. I wanted to reassure him and let him know he had a future when he felt he didn't. They didn't expect him to live longer than a couple of years; this was the information in the news at the time, everywhere you looked it was a headline 'aids epidemic' 'another person has died of AIDS'

ANONYMOUS

every time he had pneumonia and was hospitalised I was scared of what was going to happen.

35. My former husband has since passed away which obviously made things harder for

S

His father was a helicopter pilot and had a heart attack which resulted in him suffering brain damage. He was unable to work after this. This obviously had a big effect on

S

and I both emotionally and financially.

36. My mother wasn't the type of person you would discuss things with and my father wasn't around so I had nobody to speak to about anything, I was on my own. I left home when I was 14. I did not have anyone to rely on or talk to.

37. Because of the nature of S's illness people were not sympathetic, in the 1980's people didn't know about HIV and made uneducated assumptions.

38. I ended up being sterilised at the age of 32. I felt like it was my fault S had to go through this ordeal, and he had Haemophilia because I carried the gene. I didn't want to have any more children who could suffer in the same way. S's infection deprived me of a further family

39. Whenever I was at work I would get called out when he was skipping school and later on when he was in hospital a lot I'd have to be there with him. This meant that S's infections had a financial impact on me. I lost earnings when I had to take time off work and there were the additional costs of going to hospital and having to travel to London. It has had a substantial financial effect on both of us. He is not really on a living wage, he is on disability benefits and he still doesn't like telling people why he is disabled.

Section 6. Treatment/Care/Support

40. GRO-B offered us really good care. However It meant we had to travel to London for any decent treatment for S's HIV. It was an additional expense and receiving treatment became an obstacle. Lack of facilities in the local area made travelling to London a necessity. GRO-B Hospital didn't have the appropriate facilities.

41. As far as I am aware S was never offered any psychological help or counselling after being infected with HIV and Hepatitis C.

ANONYMOUS

42. I have never been offered psychological help or counselling in relation to S or his Infections.

Section 7. Financial Assistance

43. S was party to the HIV litigation that ended in 1991. He was made to sign a waiver as he was told if he didn't he would not receive any money. He was GRO-B at the time. He received a nominal amount of compensation as he wasn't expected to live long enough to need more. I believe he received around £20000. This would have been from the MacFarlane Trust.

44. S was also awarded £15,000 as a result of a medical negligence litigation, but I am unsure of the details. He was given this money because he was not expected to survive for more than 6 years after this date.

45. The amount received was not right. Making him sign a waiver and giving him less because they didn't expect him to survive is terrible. Instead of being compensated S has always had to ask and been made to beg for help which should have been given to him.

46. I have never received help from anybody else.

47. Even if I was given compensation it doesn't alter the fact of what's happened and how our lives have been affected.

Section 8. Other Issues

48. Due to S's infection through contaminated blood he has never been able to obtain life insurance, or a mortgage or anything that requires a similar risk assessment. This makes his life difficult.

49. Someone needs to be held accountable for what happened. I believe those responsible were aware in the late 1970's of what was going on, We need an explanation why they were still using blood known to be dangerous? People in other countries have gone to jail for the exact same thing, I want to know why there have been no similar repercussions in the UK.

ANONYMOUS

50. I want the truth to come out. Why was a minor given blood products without parental consent? For something that had potential of such terrible consequences I should have been notified before [S] was given any treatment. Had he not been given this treatment his whole life could be completely different.
51. The Government needs to be held accountable and so do those who made the decision to give a child who wasn't even known to have Haemophilia at the time these blood products.
52. The whole process has made us rather cynical which makes us doubt that the Inquiry will really look into this properly.

Anonymity, disclosure and redaction

I wish to remain anonymous and 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

31-05-2019