

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1792001

Exhibits: 0

Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B and I live with my husband at GRO-B
GRO-B My date of birth is
GRO-B 1944.
2. I make this statement in relation to my sons, GRO-B:S1 (DOB GRO-B 1969)
and GRO-B:S2 (DOB GRO-B) who have both been infected with HIV
and Hepatitis C as a result of receiving contaminated blood products.
3. My sons have both provided separate statements to the Inquiry.
4. My husband, GRO-B has also provided an impact statement to the
Inquiry.
5. This statement has been prepared without the benefit of access to
S1 and S2 full medical records.

Section 2. How Affected

6. [s1] was approximately 7 or 8 months old when I went back to part time work and during this time my friend used to look after him. One day she was very distraught and said that his side was all black from bruising but she didn't know what happened. We did not know it was an internal bleed. A few weeks later a lump on his shoulder appeared which the doctors said could be an abscess. We attended Hitchin South Bedfordshire Haematology Centre where the doctors pricked his ear and it didn't stop bleeding for 9 hours. Dr Fagg diagnosed [s1] with Von Willebrand's Disease (which later turned out to be a misdiagnosis).
7. During one visit at the hospital [s1] suffered from a cut in his mouth which bled profusely. We had to wait to see someone and they packed it with gauze. The bleeding stopped but [s1] kept throwing up after I fed him with milk bottle but we didn't know why. The doctor was pushed for patients and he treated [s1] roughly. He asked the nurse for tweezers and pulled something out from [s1] mouth and placed it in the bin. As the doctor exited the room to wash his hands we looked in the bin and it looked like a long plaster. It was the gauze. It has been left in. We were shocked.
8. [s1] and [s2] were treated with Cryoprecipitate at the time. We spent many hours and many visits at the hospital with both boys.
9. When [s2] cut the inside of his mouth he received a blood transfusion at the Lister Hospital in Hitchin as his veins collapsed. The doctor had to cut his ankle to get access to a vein and when the bleeding wouldn't stop the nurses cut a Kellogg's box corner and wrapped his leg in it with cotton wool. [s2] hands were tied to restrain him. It was horrendous to see.
10. Social services were involved with my sons due to all the bruising as the hospital assumed they were being abused. We were advised to contact Great Ormond Street Hospital (GOSH) so tests could be carried out on both boys to get an accurate diagnosis. We agreed and arranged an appointment with Professor Hardisty.

11 s1 and s2 were both diagnosed with severe Haemophilia A.

12. Professor Hardisty told us that from now on we should bring both boys to GOSH to be treated. When I asked about transport (as I often had to take the boys to hospital in the middle of the night) he said that the ambulance service would be arranged to pick us up. We went to hospital 4 to 5 times per week. I felt guilty taking the ambulance off the road for so long but we couldn't fault them and we relied on them a lot. Until this point we didn't feel that people were taking us seriously in hospitals. We put Professor Hardisty on a pedestal and thought that he was next to God. He was fabulous and we couldn't say anything bad about him.

13. During another visit to GOSH we were taken into a consultation room and we were told that a new treatment called Factor VIII concentrate was available instead of Cryoprecipitate. Dr Letsky, who was one of Professor Hardisty's registrars, told us that it would change the boys' lives forever as they would be able to go on holidays and we could take the treatment away with us.

14. My husband was adamant that he did not want the boys to take anything other than Cryoprecipitate and felt dubious about the new wonder treatment. But we were informed that Cryoprecipitate was being phased out and that the boys would therefore be put on Factor VIII anyway in due course.

15. We were not informed about risks involving treatment with Factor VIII.

16. Over the years both boys were treated with Armour, Alpha, BPL Factor VIII concentrate. They were put on home treatment. I injected them. I learnt how to do it even though I hated needles. Later, once we knew about their infections, I felt that every injection I gave them was like Russian Roulette. I have felt a lot of guilt over the years about injecting them with potentially infected products.

17 s2 was 18 months old when he wouldn't stop crying at night. He wasn't hungry and he didn't need his nappy changing. My husband became frustrated as it went on for a few nights. He suggested we should take him to

the hospital until they find out what is wrong with [s2] as his behaviour was unusual. [s2] was put in an isolation unit with barrier nursing and I was told that he was suffering from Hepatitis Australian Antigen. He looked yellow. Dr Hann was in charge of this and he said that the virus was in [s2] blood. When he lay down we assumed he was crying because the liver pressed on him and it hurt. We were not provided with information in relation to how to treat it or whether anything could be done.

18. Following this visit, I brought [s2] home and we thought that [s2] was going to die.

19. When [s1] was 5 years old he suffered from severe nosebleeds and we would often attend GOSH to cauterise his nose with cocaine. I rang the hospital because I couldn't mop the blood quickly enough. The ambulance driver had to open the doors and everyone was staring at us. He had lost nearly half of his life blood.

20. I was up at the hospital with one or other of the boys 4 or 5 times a week. When I called the ambulance headquarters to arrange transport to the hospital the operator used to say to me "which one this time?"

21. When [s1] turned 14 years old he attended the Royal Free Hospital to have his knee operated on by Mr Majwick. A year later, [s2] also underwent an operation on his knee.

22. After the surgery on his knee, [s1] was due to go home and we went up to collect him. We went to the Haemophilia unit and just as we were going to go we handed in the records and a sister stuck her head through a window and asked "*Would you like to know the boys' HIV test results?*". She walked past us and said "*they are both positive, see you soon*". I didn't even know they had been tested. Many people were around us and overheard it. It was horrible but this was our life.

23. Nobody has ever clarified anything to us about HIV and AIDS. We had to learn it all ourselves. After we were told about HIV we went back to find out

more but no one would be honest with us. We were not provided with any information in regard to prognosis. We weren't told to take any extra precautions or anything. They gave me some gloves to use at home – that was it. I don't know how I didn't get contaminated. At times you didn't worry about gloves you just tried to quickly get towels to cover blood.

24. I wouldn't have ever consented to the boys having Factor VIII if I knew of the risks. I would not have taken the risk for my boys. As far as I know there was never any problem with Cryoprecipitate so I would have continued treatment with this instead. There would have been a lot more people still alive if they had continued taking Cryoprecipitate.

Section 3. Other Infections.

25. I do not know whether s1 or s2 were exposed to any other infections but I am aware that s1 had CMV. He was very ill at the time and I nursed him at home. I even hooked up a drip to the chandelier in our living room.

Section 4. Consent.

26. Both s1 and s2 were tested without my informed consent. I questioned why the nurses always took so much blood from them but they just said it is for tests to ensure that everything is alright. I assumed this was routine practice for all haemophiliacs.

27. I've never been tested for HIV. When the boys first went to Royal Free I remember giving some of my blood to someone but that was all and no one told me the reason behind this.

28. I found that I was bruising easily and I was diagnosed as a mild haemophiliac I think. I carry a card with me which says "Factor VIII deficiency."

Section 5. Impact

29. I have spent my whole life waiting to lose my kids. I've spent a large proportion of my life in hospital with the kids with no regard for time. My husband hasn't been very supportive as he has spent many years in denial. If I said that the boys could die, he wouldn't hear it.
30. After I had found out they had been infected with HIV I brought boys home and the first person I spoke to was my neighbour GRO-B. He was appalled that it was revealed to me in front of everyone.
31. The hospital staff included us with the same people who had been infected with HIV through intravenous drug abuse. Haemophiliacs were lumped in with drug addicts, prostitutes and dangerous people. The stigma at the time was horrendous. We had seen all the TV campaigns against people infected with HIV.
32. Campaigning has made the boys distant as the years have gone by. They each want justice but are trying to achieve it in different ways. They don't speak to each other anymore and we are caught in the middle. It breaks my heart. This scandal has destroyed my family.
33. We didn't tell many people, we kept it within our immediate family and very close friends. We lived in a façade, we lived and laughed but just wanted to scream when people made jokes about HIV and we had to bite our tongue. We wanted to scream at people's ignorance. It was a nightmare.
34. Our whole family was stunned because no one really understood what HIV was as we were not invited to a follow up conversation about either boy. It was just a word to us. No one took the time to explain it.
35. When s1 had a chest infection we were seen by a locum doctor. She acted fine to begin with but when I said he had HIV she took a few steps back and said she couldn't help and then just left.

36. When I wanted to sign s1 up for school I told the headmistress that he was a haemophiliac. She was dubious and told me that she will need to get some instruction for that. I told her this was the reason why I enquired a year prior to him starting education. He eventually got permission to start at the school and he was given a welfare worker.
37. I remember s1 not being allowed to go to school for a few days as there was a commotion with a child's dad refusing to send his kid to a school because s1 was there and the media had linked haemophilia to HIV. The boys had home schooling at times too when we had problems.
38. GOSH said there was a college in Hampshire if we wanted to send the boys there. Me and my husband decided against it. It seems to me that they wanted people to come to be tested as lab rats. We said no and didn't want the boys away from us. I believe if we had sent them to Treloars they would both be dead by now.
39. Before s1 left school, one of the careers people asked s1 what he wanted to do. s1 said that he wanted to be GRO-B. The career advisor told s1 not to get his hopes up. It was as if these haemophiliacs were just a hindrance to everyone.
40. s1 was the first haemophiliac employed by the GRO-B. He got selected as they liked his character and his manner. He completed placements there and did bits in each department. He was very proud of his job but he eventually lost it because they found out about his HIV status. He was heartbroken. He got another job at a firm organizing conferences; they got rid of him due to him taking medication. Following this he went to work at GRO-B but again his HIV status became known and he lost his job.
41. When s2 left school he knocked on doors locally to see if any firms had vacancies. One firm providing disability services hired him. He became a HGV class 1 driver and worked for a firm at the time on their pull and drag lorries. He was then employed in a similar role for Curry's PC World. He had to give it

up in the end due to the hours as his health was deteriorating. HIV won again.

42. When [s1] left the Royal Free and went to St Thomas' he had a file review and because of the animosity between [s1] and the health professionals they didn't like when [s1] asked questions. [GRO-B]

[GRO-B]

43. I underwent another 6 weeks of counselling to deal with my depression and PTSD. I tried to get the process started in order to help myself. There are times when all of this gets to me. I have had to be a fighter. I should be looking after me more but I continue to look after the boys.

44. [s2] was involved in the [GRO-B] when he was 14 but he didn't suffer from any injuries. When [s1] was in [GRO-B] survived a [GRO-B] We have had to survive a lot as a family.

45. In January or February this year, [s1] and his partner [GRO-B] went to Phuket, Thailand. [s1] health was deteriorating and suffered from bronchitis with complications. I know that every time he's ill he thinks "am I going to die from this illness?"

46. [GRO-B] had been [s1] rock as [GRO-B] s for [s2]

47. It was essential for my husband to continue working so I took it upon myself to look after the kids. We would just deal with whatever came up for the boys. We could never plan anything because we lived such a short term life.

48. I don't wallow in self pity and I still work. I am a teacher and sometimes I see kids with Von Willebrand's Disease and Haemophilia so I do my best to make the school understand what these kids need.
49. After and were born I had two terminations due to the boys being haemophiliacs and underwent a hysterectomy in 1991. I didn't want to go through having another haemophiliac child or a daughter who was a carrier. I didn't want anyone else to go through the same pain as or it would have been too hard.
50. While was still living at home he was taking the AZT treatment for HIV. We heard stories that the AZT was killing people more than the actual infection and whenever there were any changes with treatment we would panic due to the history. We also worried that they were trying to kill everyone off to bury this scandal.

Section 6. Treatment/Care/Support

51. attended GOSH and had all his teeth taken out at the age of 9. The dentist said his next teeth will come through straighter and stronger. was taken in at the same time and only had 2 taken out. Following this, their teeth never came through properly.
52. I never was offered any counselling or anything. I didn't think it was any good. I ended up seeking help myself and I attended counselling for 6 weeks in Stevenage but didn't get anywhere so I stopped.
53. I had to cope with everything; I have never been offered any help at all.
54. I feel that I need proper psychiatric help – not just counselling. I believe I am suffering from PTSD. There are times that it really gets to me. I've had to be a fighter but, at my age, I shouldn't have to be. I should be looking after myself and my husband. I feel tired all the time.

Section 7. Financial Assistance

55. The social worker brought me some paperwork to fill out for attendance allowance but I only filled out one as I felt it was too greedy to apply for each of the boys. The social worker encouraged me to submit two applications. They received the attendance allowance and also received mobility allowance.

56. [s2] got turned down for PIP payments and I still don't know why.

57. The MacFarlane trust always said they can't give us any money. We have had to jump through so many hoops and we always had to justify things. [s1] house was flooded after his ankle fusion. He had to move out but they said they couldn't help and were only prepared to loan the money.

58. We were involved in the 1991 HIV litigation. My husband and I signed the waivers which was blackmail. We were told that no one would get anything unless everyone signed the waiver.

59. [s1] and [s2] were involved in the HCV litigation. It was blackmail again. They were asked to sign a waiver. [s1] signed it but [s2] refused to and therefore didn't receive any money.

Section 8. Other Issues

60. I get very cross when I hear things. Some years ago I heard about vials of contaminated blood being shipped out to Africa because the mafia were involved. The place where the blood was supposed to be kept was infested with rats and old paint contaminating the blood.

61. I've been to Downing Street, Trafalgar Square and Royal Courts of Justice with my placards and campaigning and I attended the first day of the Inquiry.

Anonymity, disclosure and redaction

62. I would like to apply to retain my anonymity. I understand this statement will be disclosed and published as part of the Inquiry.

63. I would like 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... 14th August 2019.