

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1744001

Exhibits: 0

Dated: ~~June~~ 2019
3 July

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 and I was born on GRO-B I live at GRO-B
GRO-B I have two children,
GRO-B GRO-B grandchildren and GRO-B great grandchildren. I
divorced in GRO-B and over the years I have worked GRO-B
GRO-B but am now retired GRO-B lives with me
and cares for me.

2. I make this statement in relation to GRO-B:S
S who was born on GRO-B He had severe Haemophilia A
and was treated with contaminated blood products, as a result GRO-B
GRO-B

3. I am aware that GRO-B has also provided a
statement to the Inquiry.

4. This witness statement has been prepared without the benefit of access to [S] full medical records.

Section 2. How Affected

5. [S] was diagnosed with severe Haemophilia A aged [GRO-B] after he broke his leg and it failed to heal. His X-rays did not show any issues and so [S] was sent to [GRO-B] to see why it was not healing. He was diagnosed there and received treatment from [GRO-B]. I did not even know what Haemophilia was when he was diagnosed with it. I just know it took many weeks for his leg to heal.
6. The next incident I remember was when [S] having an issue with his tooth and his gum was bleeding. I remember that a policeman who attended the scene asked if he could follow us to [GRO-B] as he had never heard of Haemophilia.
7. We arrived at [GRO-B] and there was blood everywhere as [S] gum would not stop bleeding; the paramedics did not know how to stop it or why it was happening. The policeman saw the blood and he passed out. When he eventually came round he asked if he could call the station to have more officers come to the hospital to witness [S] condition. We agreed and so more policemen came to see what was going on. Eventually the doctors at [GRO-B] managed to stop the bleeding and after a while they sent us home.
8. Originally [S] was treated with cryoprecipitate at [GRO-B]. The earliest treatment which is shown on the records received from UKNHDO National Haemophilic Centre ("NHC") is [GRO-B] but I know [S] received treatment before then. [GRO-B] spent two years trying to get [S] medical records but never managed to obtain them.

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9. [S] also received treatment from [GRO-B] as they were the specialist Haemophilia hospitals.
10. [S] started receiving Factor VIII concentrate in the early [GRO-B]s when he was [GRO-B] years old. Even after [S] started receiving Factor VIII treatment he still received cryoprecipitate for a while too.
11. [S] received blood products from around the age of [GRO-B] until he died in [GRO-B].
12. No information was ever provided to me about the risk of being exposed to infection from receiving blood products.
13. As a result of receiving blood products [S] was infected with the Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV) however I only discovered [S] had been infected with HCV about a year ago. [GRO-B] joined the Face Book Tainted Blood Group and someone in the group mentioned something about the Skipton Fund, who we had not heard of before. They also mentioned that people who were infected with HIV were almost invariably infected with HCV too. [GRO-B] researched this and eventually found records that proved this to be correct.
14. From the records I have seen, it shows that [S] was diagnosed with HIV on [GRO-B]. I remember one day that [S] went to [GRO-B] for a regular blood test with his wife [GRO-B]. They were at the hospital all day and their absence caused me to become worried so I rang the hospital. I was told that [S] was on his way home and he had bad news. I do not know when he was told he had been diagnosed with HIV but I presume it was around that time, [GRO-B] as I was looking after [GRO-B] children ([GRO-B]) while he went to the hospital and they were very young. [GRO-B] was born in [GRO-B] so this fits with that timeline.

15. When [S] came back from the hospital he said he did not want to talk about anything or discuss it, so I did not. Due to the publicity at the time, I felt I knew what the 'bad news' was that I had been warned about by the hospital. I effectively knew but it was not spoken about. He soon made a will but he repeatedly said 'we will not speak of this'.

16. I believe [S] consultant, [GRO-B], had said not to tell anyone and certainly it was not the right time to tell his children. Other than that I believe the doctors said very little and no information was provided to [S] about the infection as far as I am aware.

Section 3. Other Infections

17. Due to the fact that we were never informed that [S] had HCV, he could also have been exposed to vCJD without our knowledge but I do not know.

Section 4. Consent

18. I do not know if [S] was ever tested or treated without his knowledge or consent but as he was not even told he had HCV I am not sure that he would have had knowledge of the exact tests or treatment he received.

19. From [S] NHC records there is reference to [GRO-B] research work; however I am not sure what this is.

20. [S] had multiple blood transfusions due to his Haemophilia condition as well as regular blood tests but I do not know what for.

21. When you are in hospital as often as [S] was, things are hard and you are not always exactly aware of what is going on a lot of the time. Most of the time you would not be told anything unless you specifically asked.

22. From a Haemophilia point of view he was well looked after.

Section 5. Impact of the Infection

23. [S] diagnosis caused a big change in him both mentally and physically. He became very quiet and distant. Nothing was ever really discussed in front of me or his children and he became quite withdrawn. He was very strong mentally but he had a temper and I remember it well.

24. [S] always kept everything to himself and was so stubborn about everything. We never knew how much he was really suffering; especially just before he died. We later found out that he should have been in hospital but he did not want to be there over Christmas.

25. He told me that he had written a letter stating he did not want to be kept alive or to be resuscitated or have a life support machine used on him should he ever get to such a stage.

26. He was the same with his children in that they did not know about his condition but he was preparing them for the time he would not be there for them. He asked them that if something should happen to him, would they be happy to live with me, their grandma? The children did not know what he meant and they became upset.

27. [S] wife [GRO-B] left him in [GRO-B] it seems she could not deal with the stress of [S] living with HIV. He was devastated, it was the only time I saw him cry, he was normally so strong. [S] obtained custody of their children, he was a brilliant father, and he brought them up with my help, I lived next door. [GRO-B] though was the main bread winner, which was also difficult and put a strain on the relationship [S] was unable to work due to his health.

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28. [S] was a very private man and was very careful with money, he had to be. He never let you know what he did or did not have. He used to have nightmares that he was going to talk in his sleep and give his pin number out.

29. [S] would become very tired and fatigued. Travelling up and down to London for treatment and looking after his children too did not help with this. [S] was constantly in pain; he was very brave. He just became skin and bones really as he lost a lot of weight; that was when he knew he was coming to the end of his life.

30. He never feared death but he feared leaving me and his children behind. Towards the end of his life he did not sleep as he was scared that he would not wake up. He stayed downstairs for the end too as it was too difficult for him to get upstairs. He would have to go up the stairs on his bottom a lot.

31. [S] died at home on [GRO-B]

32. Once I was staring at him and he told me not to look at him, so I lied and said I was not; but I would just watch him. I was seeing changes in him. This was just after [GRO-B] just before he died; the image is so vivid in my mind. He went to sleep that night and he never woke up. The day before we had no indication that he was about to die. He did not open his eyes but I saw a tear. It was shocking.

33. When [S] died I was appointed the children's guardian under the terms of [S] will and his house was left in trust to his children until they were 21. My other son, [GRO-B] lived in my house and I moved [GRO-B] into [S] house to look after his children.

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34. I always told the children that [S] had died of pneumonia and I only recently told them that he had HIV. His death certificate says AIDS and pneumonia. I took that burden on myself.

35. I do not know if [S] ever received any treatment for HIV. I only saw him doing his home treatment of Factor VIII.

36. [S] did not work. He used to be a butcher and then a surveyor on a building site until a crane hit him and he needed an operation on his leg to insert a pin. His foot was twisted round and his mobility was restricted. After this incident he did not work again. He could not bend his leg and I think his Haemophilia started to catch up with him too, in addition to the HIV.

37. [S] was very clever he attended [GRO-B] a private school and he did very well so could have been very successful even though his Haemophilia limited him. When he became a surveyor with his condition we could not tell him he could not do it. He wanted to do his job even with his condition.

38. No one knew of [S] diagnosis. The stigma attached to HIV/AIDS at the time was very bad but no one really knew about [S] status. People maybe assumed but [S] was very private. If anyone knew, no one really asked, even if they did make the assumption. Not a single person asked me what he died of. I think they maybe all knew but it was just unspoken. I do not think that he told any of his friends so only his immediate family knew and his children only found out recently.

39. I recall [GRO-B] came home from visiting [S] in hospital and came home and was crying, he told me that he had read [S] hospital notes which said that he was going to die soon. He said nothing else and went very quiet. [GRO-B]

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and [S] never spoke of it directly; it was always a taboo subject and always on the television, always in a bad light.

40. After [S] marriage broke down he never became involved in any new relationships. He was also always in and out of hospital.

41. The impact on me was significant. I did not take his illness on board at first but I tried my best to look after him and the children as well as I could, there was nothing more that could have been done for him.

42. It does hurt me knowing that [S] never got to see his children grown up or see his grandchildren as he was very much a family man.

43. When [S] died in [GRO-B] I left my family home to take care of his children permanently. I was almost [GRO-B] years old and the children were [GRO-B] and [GRO-B] I should have been enjoying my retirement but instead I took on his children.

44. I struggled financially, I was working nights at the time but had to give up working to look after the children. I used all my savings for the upkeep of the house and the children.

45. I qualified for family allowance when I was looking after [S] children but my pension was deferred as I was receiving this allowance.

46. It was a very difficult time for me. I cried everyday. I wanted to stop living and the only reason I did not was for the children. I was heartbroken and just felt awful.

47. [S] should have lived far longer. I thought we would have more time with him. I was devastated.

48. I lost the opportunity to be a grandparent to [GRO-B] and [GRO-B] and to spoil them. I had to be strict and had to be their mother, father and grandmother. I should not have had to do all that.

49. The children did not know much at the time and I think that was for the best [GRO-B] [GRO-B] also recommended that I not tell the children straight away and I believe that this allowed them to have a more stable upbringing that it could otherwise have been.

50. [GRO-B] was devastated. He suffers with psychological problems and he had a breakdown, I do not know if it was connected to [S] dying. He will not talk about it. He is a gentle giant and is on medication for this mental health but he has had his own problems. Every now and again he gets flashbacks.

51. [GRO-B] died in [GRO-B] of liver problems. I was told she died from a non-alcoholic fatty liver. I am not sure if there was a link to [S] condition.

52. [GRO-B] also suffers a lot from mental health problems as a result of [S] death. [GRO-B] also suffers significantly and was under a lot of stress from everything.

53. I returned to live in my own house in around [GRO-B] it was a slow transition. There were more tears and I was back and forth between the two [GRO-B] homes until I settled back to live with [S] leaving the girls to live in their home.

54. [GRO-B] still lives [GRO-B] with her long term partner and their two children, while [GRO-B] lives locally with her husband and their one child.

Section 6. Treatment/care/support

55. We were offered no support or care from anyone for [S] or myself. Neither of us were offered counselling either.

56. There was so much that could have helped, even just little things were so hard for us on a daily basis. I feel something should have been provided and it was just so awful that nothing ever was.

57. I believe that there were care workers and dentists that refused to help and treat [S]. All his dental work was always done at [GRO-B].

Section 7. Financial Assistance

58. [S] received £80,000 from the MacFarlane Trust. This money effectively paid for the house that [GRO-B] still lives in, and for the girls' education as well as any maintenance problems such as replacing the boiler at home. By the time the children were [GRO-B] almost all that money had been spent. I believe the money was from the [GRO-B] HIV litigation and that [S] had to sign a waiver.

59. When I was living with the children I applied for grants from the MacFarlane Trust. After [S] died we applied for a grant to have the house decorated and for a new bed and carpets. A solicitor helped me with all the paperwork and application process which was successful.

60. As stated above I have recently found out about the Skipton Fund and [GRO-B] started the process of applying for the Stage 1 payment about two years ago. We could not get the evidence they needed and then finally the NHC records were received and so last summer the application was finalised and it was successful. We received £20,000 from them and we split it three ways between [GRO-B] [GRO-B] and myself. I did not want any of the money but the children insisted that I use it, at least I have been able to replace my savings for my funeral expenses.

61. I believe that there should have been a lot more offered financially; especially now that I have gone over all the details and everything is coming back to me to make this statement. Nothing was ever offered to us; we were left to fend for ourselves, it was outrageous. Day to day we were living my on my savings which were used so quickly. We could only ever buy essentials and it was such a bitter pill to swallow. I refuse to get into debt and leave it here for the children. I would never do that.

Section 8. Other Issues

62. It is not right that I was not told that [S] had HCV. No one helped or considered our position when we were going through so much. Going through our grief with the financial worry on top of everything added to the stress.

63. Even now this whole ordeal just eats away at me. I will take it with me when I die. I cannot believe people were able to get away with it. I am very bitter especially as we did not know [S] had HCV as we only found out about this from the medical records a year ago.

64. I am [S] [GRO-B] and I did not know that he had HCV and I feel horrible about it. He survived so much and then to find this out was so hard.

65. I will not let this go and if I could do anything about it then I would. Factor VIII was a treatment for Haemophilia; it should not have caused all this.

66. I believe the fault lies with the Government, they were responsible for a lot of this and in the way that they handled it.

67. Now I believe that I ought to be compensated for what has happened. It is not so much about the money but it would have helped me so much in my situation. I lost a beautiful son and that was hard enough.

68. The last year has been hard for me. I cannot walk anymore. I am GRO-B years old and have been having health struggles especially during this last year.

69. I appreciate what I have but I realise that I could, and should have had so much more especially now that I am in ill health and I have no savings, I am struggling. I cannot afford to look after myself or get a car which can hold a wheelchair. After everything that has happened, it is not right.

70. Any money that comes from this for me should go to the children GRO-B and GRO-B as I might not be around but I want the children to have it.

Anonymity, disclosure and redaction

71. I confirm that I do wish to apply for anonymity.

72. I do wish to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

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

Signed.....

GRO-B

GRO-B

Dated: 3 July ~~June~~ 2019