

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1232001

Exhibits: 0

Dated: April 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 live at GRO-B
2. I GRO-B in GRO-B and have GRO-B I am currently working.
3. I make this statement on behalf of my late father, GRO-B: F He was born on GRO-B and GRO-B on GRO-B aged GRO-B as a result of being infected with HIV and Hep C by contaminated Factor VIII (FVIII).
4. My mother, GRO-B has also produced a witness statement to the Inquiry, GRO-B
5. This witness statement has been prepared without the benefit of access to my late father's full medical records. If and in so far as I have been provided with limited records the relevant entries are exhibited to this statement in the medical chronology.

Section 2. How Affected

6. My father was diagnosed with very mild Haemophilia at the age of [GRO-B]. His clotting factor was [GRO-B]. He led a normal life and actively played contact sports such as rugby and never really had any problems associated with his Haemophilia.
7. He was treated at the [GRO-B] at the [GRO-B] [GRO-B]
8. He only received FVIII concentrate on [GRO-B] at the [GRO-B] for a [GRO-B] and the [GRO-B] for an [GRO-B] to [GRO-B] [GRO-B] at the [GRO-B]. I believe my father was infected with Hep C and HIV during the eye procedure at the eye unit. I believe this because he was very ill following this procedure.
9. In [GRO-B] my parents received a letter from a Dr [GRO-D] at the [GRO-B] stating my father may have been infected with HIV and was requested to have a blood test. Following the test, the results came back confirming that he tested positive for HIV. I believe he deserved more than a letter, even a phone call would have been more appropriate.
10. In [GRO-B] my father was told he had Hep C. He was having some medical complications and the doctors could not figure out what it was. They thought it was the treatment he was receiving for HIV. However, following a blood test, they found out that he had Hep C.
11. I do not believe that my father was given much information and I do not think he was well managed at all. In relation to the HIV infection, he [GRO-B] [GRO-B] and was told by Dr [GRO-D] to use condoms, not have children and not to share a toothbrush. However, at the time my parents already had me [GRO-B]. My mother was a [GRO-B] and she [GRO-B]. I believe the NHS doctors that diagnosed him and those subsequently treating him lent on the fact that [GRO-B] rather than providing compassion and support that would be common place now.

ANONYMOUS

12. I believe my father should have been given information and advice about the risks associated with FVIII prior to being treated with it.

13. As previously stated, the way the doctors communicated the infections to my father was poor. He was told [GRO-B] that he was infected and it was out of the blue. The news was life changing which should have been communicated through other means instead of a letter.

14. I was [GRO-B] Thankfully, [GRO-B] mother and I were not infected.

15. For further information in relation to this section, please refer to my mother's witness statement.

Section 3. Other Infections.

16. As far as I am aware, my father did not have any other infections. However, he ended up having a [GRO-B]
[GRO-B]

Section 4. Consent.

17. I believe that by the time my parents received the [GRO-B] the doctors already knew of my father's HIV status but failed to tell him. I do not know whether he was treated and tested without his knowledge.

18. I believe he was tested without his consent in relation to the HIV infection, but he was tested with his consent in relation to the Hep C infection.

19. My father played contact sports without any issues in relation to his haemophilia, so I do not understand why he even needed FVIII for the dental and eye procedure. I think it was quite strange that he received FVIII in the first place and that he was probably tested for the purposes of research.

Section 5. Impact

20. I wish to partly rely on my mother's witness statement in relation to this section.

21. My father suffered mental effects as a result of the infections. In or about GRO-B
GRO-B I think he was finding it hard to rationalise what was going on. By
GRO-B he was a complete shadow of what he used to be. He became completely depressed for which he was medicated. Prior to the diagnosis, my father led a normal life but following the diagnosis, he was devastated. He had mood swings and anger issues. I did not understand why what was going on at the time. I was pretty shielded from what was going on and not told anything about my father's infections.

22. My father also suffered physical effects as a result of the infections. He first had a massive weight gain and then a huge weight loss. He eventually became skin and bones. He always needed a break when we would go on long distance drives and would be tired all the time. He used to lie across the back seats just so that he could rest. He also had diabetes and I believe it was as a result of the infections and combination medication.

23. He started to deteriorate in GRO-B but his health worsened in the GRO-B
GRO-B of his life. Towards the end of his life, he had a GRO-B
GRO-B where he was kept for GRO-B My mother was GRO-B
GRO-B for GRO-B and GRO-B
GRO-B during that period. He started to get worse and lost more weight. My father wanted to stay at home towards the end of his life. I recall my father being extremely jaundiced and had bed sores all over him as he could not move, even in bed. He really struggled to do normal day-to-day tasks such as going to the bathroom. He ultimately died of GRO-B as a result of the Hep C infection.

24. My father received various anti-retroviral drugs and prophylactic drugs to prevent him from getting further respiratory infections. He received AZT for the HIV but his treatment was regularly changed. I do not know when he

ANONYMOUS

started the AZT treatment. I believe the HIV was reasonably well managed but not the Hep C.

25. My father received Interferon treatment in the GRO-B for the Hep C but it did not work for him. He then had GRO-B which also did not work but rather caused adverse reactions. As a result, the Hep C was just not being treated.
26. My father experienced difficulties and obstacles in receiving the treatment. There is a letter in his medical records where a consultant at the GRO-B was telling the GP that they could not afford treatment for Hep C for my father. My father's treatment was therefore delayed as a result.
27. My father suffered mental effects as a result of the treatment that he had. He had depression and a poor self-image.
28. My father also suffered physical effects as a result of his treatment. He got diabetes and he also suffered from oral thrush as a result of the treatment, more towards the end of his life. He also had upset stomachs.
29. I do not know if there were any other treatments which should have been made available to my father. However, there was PCP prophylactic available at the time which was delayed for some reason. I assumed it was delayed due to inexperience or incompetent staff.
30. My father's infected status impacted on his dental care. He never had an appointment at a local/private dentist after the HIV diagnosis and always had to attend the GRO-B for any dental treatment.
31. My father's infected status had an impact on my private, social and family life. I was not aware at all of the full story in relation to my father's infections until GRO-B after I received a copy of the Coroner's report. I just knew that my father was very poorly and that it was unlikely he would ever get better, and as a result he would die. However, being young, it did not really sink in and I assumed that there was some silver bullet somewhere that would help him. It

ANONYMOUS

was a difficult situation to be in. Personally, I suffered with anxiety and depression when I was GRO-B years old due to the trauma of seeing my father in intensive care and then dying. As a result, I gained weight. I went to hospital and had appointments with a psychiatrist. GRO-B

GRO-B to be looked after and picked up from school. Prior to that we lived with my parents and they would pick us up from school. Towards the last few years of primary school GRO-B was picking us up which got very confusing for me. During the last few years of my father's life, my brother and I had to return from school on our own. They did not tell us anything because they believed that we would not understand what was going on. I was oblivious as to what was going on and what was going to happen.

32. I believe that my parents did not tell many people about the infections due to the stigma attached to the HIV at the time. My mother told me that she saw HIV handwritten on my father's medical records, potentially exposing his status to other patients and visitors to the hospital. GRO-B did not even speak much about this until the Inquiry started, we both still struggle to discuss our memories, which in turn causes its own issues. Only my GRO-B knew about my father's infections as he was GRO-B at the time, so he was told in case something happened to my father. Then GRO-B became GRO-B and so he was told about the infections. Even now, I believe only about 10 people know the reasons behind my father's death. My father kept it very private and the pressure on my mother to do the same was incredible.

33. GRO-B and so I believe he would have been as confused as I was at the time, but probably had a bit more knowledge as to what was happening at home. I was GRO-B when my father died and GRO-B GRO-B

34. My father's infected status had an educational effect on me. I struggled in school in my early life with separation anxiety. The anxiety theme continued throughout my primary and secondary school life. Upon my father's death in

ANONYMOUS

GRO-B I had given up on GRO-B education and did not achieve what I was capable of (although I had done enough to GRO-B). Throughout this I had struggled with poor self-image, bullying and anxiety. GRO-B was no better than GRO-B and I did GRO-B. GRO-B Instead I worked in my GRO-B nursery. I believe that the time I spent in the GRO-B helped me better my life and therefore GRO-B. Since then, I have gained an GRO-B which leads me to believe that I was capable of more at the time of my father's death.

35. For the last portion of the year before my father died GRO-B and was not used to looking after us. She was GRO-B. She was not in a position to look after GRO-B. I was doing my GRO-B at the time and was affected massively.

36. My mother was under a lot of pressure, having left her job to become a (unpaid) full-time carer for my father as well as us. I believe this led to her GRO-B to include anxiety and depression which are still an issue now. GRO-B also felt increasingly isolated from the family as he was aware that there was a larger issue that was not being communicated to GRO-B.

37. My father suffered from work-related effects which in turn affected us financially as a family. My father was employed as a GRO-B working for a GRO-B as he worked with GRO-B. As a result, he had to give up his job as he did not want the staff to know what he was going through and he was also worried about their wellbeing and did not want to infect them. He then became a GRO-B. GRO-B He completely retired by GRO-B and I believe his pension would have been quite small as a result. Due to financial problems, there was a lot of stress and conflict between my parents over money.

Section 6. Treatment/Care/Support

38. As previously stated, there was a delay in receiving treatment. The [GRO-B] was not a liked institution as their etiquette and professionalism was bad.

39. As previously stated, there is a letter describing an argument over who will pay for my father's treatment in relation to the Hep C, the GP or hospital. I believe my father should have received funding for the treatment when the treatment first became available regardless of the costs.

40. A psychiatrist [GRO-B] approached my father and gave him psychological support but she was [GRO-B]
[GRO-B] She was available to our whole family.

41. I have [GRO-B] attended counselling sessions with [GRO-B] which I found helpful. The sessions helped me discuss what had happened as I was experiencing anxiety again. However, I have had to suspend the sessions due to the financial cost.

Section 7. Financial Assistance

42. I wish to rely on my mother's witness statement in relation to this section as she was assisting my father with the finances at the time.

43. I believe I received some school uniform grants and holiday money. I do not know which trust or funds provided the financial assistance. I never personally had the money in my bank but the payments were made to my mother for me and my brother.

44. I also [GRO-B] of which I remember nothing.

Anonymity, disclosure and redaction

45. I wish to remain anonymous.

46. I 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

28/04/19