

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1698001

Exhibits: 0

Dated: July 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 and I was born on the GRO-B I live at GRO-B
GRO-B I am
married with 3 children. I am a GRO-B
GRO-B and I work in the fostering team for GRO-B
children's social care. My son has severe Haemophilia A.
2. I make this statement on behalf of my late father, GRO-B:F who
was born on the GRO-B and died on the GRO-B as a result
of the infection that he was given after receiving infected blood products.
3. This witness statement has been prepared without the benefit of access to
late father's full medical records.
4. My sister, GRO-B has also produced a witness statement
(GRO-B) for the Inquiry.

Section 2. How Affected

5. My father was born with severe Haemophilia A. There was no treatment for Haemophilia throughout his childhood. I remember my father was about GRO-B years old when he had his first treatment of cryoprecipitate. I believe he started to receive Factor VIII concentrate in or about the mid GRO-B. He was only treated at the GRO-B in London and his treating doctor was GRO-B GRO-B.
6. I do not know the exact circumstances around my father being informed of his infection, however I know it was in GRO-B. He was infected with HIV and Hepatitis C after receiving contaminated blood products in order to treat his Haemophilia.

Section 3. Other Infections

7. My father was also infected with Hepatitis C.

Section 4. Consent

8. My father did not consent to be infected with HIV or Hepatitis C. I do not know how he was told or how long he was infected before he was told, however my mother remembers hearing about some haemophiliacs being infected with HIV and wondering if the vasculitis marks on my father's legs might be a sign of being infected. She was told that on the contrary this was a sign of the Factor VIII concentrate working well. She tells me that she realised some months later this was not true as my father's infection with HIV was confirmed.

Section 5. Impact of the Infection

9. From the time that my father was infected with HIV in GRO-B through to his death in GRO-B my father suffered from significant mental and physical effects from various infections he developed as the HIV virus turned into full blown AIDS. I was about GRO-B years old when he was told about his infection and growing up as an adolescent through these very stressful times was extremely difficult and had a lasting impact upon family relationships.

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10. I believe my parents told me of my father's infection fairly soon after they knew. I was [GRO-B] years old and finding out obviously had a negative impact on every aspect of my experience at school.
11. In or about [GRO-B] I recall my father having regular blood tests in relation to his T cell count and while waiting for these results, the family had to struggle with a huge amount of stress. We all felt that my father was about to die at any moment.
12. I recall my father had blotches all over his body when he was infected and he developed on-going complications with his immune system.
13. I know that following the infections, my father developed Cytomegalovirus (CMV) which he suffered with for a long time before his death from AIDS in [GRO-B]
14. The CMV affected his eyesight and bowels and my father was almost blind when he died. The CMV affected parts of his brain and not long before his death he had a brain scan which showed damage to a large part of the frontal lobe. Due to this damage in his last year of life he became disinhibited, grandiose and manic – at times he would talk all through the night, and he became emotionally unstable and fixed on certain obsessions and behaviours which bore no resemblance to the gentle and humorous man he was before he was infected with HIV.
15. My father received ganciclovir to treat the CMV which had side effects.
16. I believe my father was given AZT treatment for the HIV, but I do not know when he was given it. I do recall initially when he was told about the HIV there was no treatment available for it and so people just had to try and live with the infection as best as they could. My father was reasonably well up until about the [GRO-B], however the family were constantly worried.
17. The main effects of the treatments that my father received for his HIV and Hepatitis C was that they did not work – hence his death.

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18. I do remember that my father had an argument with his regular dentist because he would not treat my father because of his infected status. I do not know if he went anywhere else for further dental treatments.
19. It would not be for me to comment on the impact the HIV infection had upon my father. I know that his HIV status was something which necessarily became a secret which we as a family had to keep, and I know that my parents told few people. This was due to the stigma around HIV and AIDS at the time. The [GRO-B] were very difficult times to live through if you had HIV or were living with someone with HIV. My father's mental health was also inevitably affected significantly and he was both depressed and angry about what had happened to him.
20. As a family, we all had to be more careful being around my father. We made sure not to use his toothbrush for example, and I remember becoming quite scared that I might use it accidentally. My brother, sister and I all felt worried at times that we might become infected.
21. The impact of all this on me was enormous at the time, both mentally and emotionally. Through my teenage years I kept my family life and social life very separate and I did not feel able to tell any friends about my father's HIV status or even my boyfriend until I left home to go to university. I really felt that I lived a double life – and remember going to the cinema with friends when I was [GRO-B] and seeing the big iceberg advert with the 'Don't Die in Ignorance' slogan. I had just come from home where we were waiting to hear about my father's latest test results. Of course I was not able to tell my friends what impact the advert had on me. All of this meant that it was hard to grow up, to separate and to be free to be teenage as there were such serious things going on at home. I managed the best I could by kind of dividing myself between home and friends and not really letting the two meet. The fact we had to keep this big part of our lives secret in order to protect ourselves from the hatred of others was not good. Secrecy is not healthy. However things were crazy in the 1980s where HIV was concerned – people thought it was possible to catch it from anything. The media portrayal was dreadful.

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22. I was never offered any counselling or support for myself and I think this would have helped. The whole family were very wrapped up in my father – especially my mother and this badly affected our adolescence.
23. My father died when I was [GRO-B]. Neither myself nor my younger siblings had got married or had any children at that point and so my father never had the chance to meet our partners or children. This has had an ongoing impact on my adult life; I do not have a father anymore and it is unbearably sad to think that he does not know us as adults, and that he did not meet his grandchildren.
24. My mother was with my father from the age of [GRO-B] years old and they were together for approximately 35 years. Understandably it has been extremely hard for my mother to lose her husband and she continues to miss him hugely.
25. Around 6 months after my father's death, my mother sold the family home and moved up to [GRO-B] to be closer to me. My sister came to live with her.
26. As my father's health began to deteriorate, he was forced to stop working. This had a huge financial impact as the burden fell on my mother. She had her own business and had to close it to look after him. With both parents out of work, we did struggle financially. My father was never able to get any life insurance.
27. I was working when my father died and I was traveling back and forth from my family home in [GRO-B] to my house in [GRO-B] where I was teaching. This really affected my ability to concentrate and work well and efficiently.

Section 6. Treatment/care/support

28. I believe that my father's dental care and his day to day dealings with his GP became difficult. We lived in a little village and my father's GP was also a family friend.

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29. My father was provided no support in relation to the infections as far as I am aware.

30. As I have said I was not offered any counselling or psychological support but I do feel that I would have benefitted from it had it been offered to me.

31. I felt so alone and needed some acknowledgement of the difficulties and struggles I had to endure which were separate to those of my mother and father. It would have definitely helped me to talk to someone.

Section 7. Financial Assistance

32. I believe my father received some financial assistance from the Macfarlane Trust but I am unsure of the amount. I do remember he received an out of court settlement sum not too long before he died. I believe the out of court settlement was part of the 1991 litigation.

33. Any money that my father did receive was given to him on the basis that this was an end to the matter.

34. I have not received any financial assistance from any of the trusts or funds that were set up.

Section 8. Other Issues

35. I hope that this Inquiry will provide us with some answers and hold the right people to account to what happened.

Anonymity, disclosure and redaction

36. I wish to remain anonymous.

37. I would like to provide oral evidence to the Inquiry for the sake of my father, should I be called.

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Statement of Truth

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

Signed...

GRO-B

Dated

26/7/19