

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3005001

Exhibits:

Dated: February 2020

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 with my husband and youngest daughter. We also have another daughter who lives in her own home.
2. I make this statement in relation to my late father, GRO-B: F who was born on the GRO-B and passed way on the GRO-B My father was infected with HIV as a result of contaminated blood products. I also believe he was infected with Hepatitis B (Hep B) and Hepatitis C (Hep C).
3. I am aware that my mother, GRO-B, has provided a witness statement to the Inquiry.
4. This witness statement has been prepared without the benefit of access to my father's full medical records.

Section 2. How Affected

5. My father was diagnosed with severe Haemophilia A when he was a young child - I am unsure of his exact age at the time of diagnosis.
6. My father was initially treated with cryoprecipitate at GRO-B and his treating doctor was GRO-B In or about the late 1970s/early 1980s his care was transferred to the Royal Liverpool Hospital (RLH) and his treating doctor was GRO-B I believe it was in the RLH in the 1980s that he received his first Factor VIII (FVIII) treatment.
7. My father was told by the doctors that he was probably infected with HIV when he received large quantities of FVIII for a kidney surgery in 1984. However I believe he could have been infected at any time through any of his regular treatments he had with FVIII.
8. My father also had home treatment and he would treat himself as and when he had a bleed, which was quite regular.
9. My father was assured by his doctors on multiple occasions that there was no risk of contracting HIV from his FVIII treatment.
10. As a result of my father receiving FVIII blood products he was infected with HIV. As stated above, I also believe that he was infected with Hep B as I know he had antibodies to this virus in his blood and although he was never diagnosed with Hep C as the test was not available until after his death, I believe it is most likely that he was infected with this also.
11. I believe that my father was told that he had HIV soon after he was tested. He was completely distraught when he found out about the infection.
12. In the mid 1980s when the news of the spread of AIDS in America began to surface, I believe my father asked his doctor at the RLH about the safety of FVIII on about three different occasions. He was obviously concerned because of the source of the product. Each time he was given assurance that the treatment he received was safe. In fact at a general meeting with doctors

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and other patients which was held to address these concerns, one of the medics apparently made a very inappropriate and insensitive quip: "What's the problem, are the Haemos frightened of becoming homos"! That statement was wrong on so many levels!

13. I think it was in March 1986 that my father was advised to be tested for HTLV-III (as it was called then). At that time test results were not available for about two weeks. My mother was advised to wait for my father's results to determine whether or not she should be tested. I can only imagine what an awful period of time this must have been for them both. I think my mother should have been given the option to be tested at the same time rather than waiting for my father's results. When my father's results came back positive they then had to endure another 2 week wait for my mother's results.

14. I wish to rely on my mother's statement in relation to what information and advice was provided, if adequate information was provided to understand and manage the infection and what information he was given about the risks of others being infected as a result of the infection.

Section 3. Other Infections

15. As stated above, I believe that my father was also infected with Hep B and C. However, he passed away before a test was available for Hepatitis C.

Section 4. Consent

16. I do not believe that my father was tested without his consent. I do think that the way my parents were tested for the infection was wrong, because my mother had to wait two further weeks for her results.

17. I do not know if my father was given full or adequate information.

18. I do not know whether my father was tested for the purposes of research.

Section 5. Impact of the Infection

19. My father's infections were not revealed to me or my younger sister at the time when my father was told, in an attempt to protect us both I imagine. We were only 18 and 14 years old at the time.

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23. My father suffered terribly psychologically after being told that he was HIV positive. He was a worrier by nature as it was so you can imagine the impact that this had on him. When he used the toilet he would pour copious amounts of bleach down it afterwards and the same after taking a bath. He also had his own set of towels and cutlery/crockery. It was extremely distressing not to be able to reassure him that none of these measures were necessary – he was just not prepared to take any chances.
24. Physically he suffered with a lot of sore throats and oral/oesophageal thrush. He was prescribed AZT but was unable to carry on taking it as it made him very anaemic. There was no other treatment option available at that time.
25. In GRO-B my father lost his younger brother to AIDS. He was also infected through contaminated FVIII blood products. My uncle suffered great physical effects of the illness, he became skeletal, went blind and was bedridden. I believe that witnessing this had a devastating and traumatic effect on my father as I think he saw what the future held for him. Although his health had been deteriorating, I think this accelerated his illness and he was hospitalised in November/December of that year with oesophageal candida.
26. My father returned home for Christmas but was admitted to hospital again in the New Year. He died on the GRO-B aged GRO-B. Although he was quite ill, we did not think that his death was imminent. He was sitting up in bed on the afternoon of the GRO-B chatting to my now husband GRO-B but by the time my mother went to visit him at teatime he had deteriorated rapidly and had been moved to a side room - he was barely conscious. When she was fixing his blanket she said she noticed that his back was completely

black and blue and she asked if he had fallen. She was told that he hadn't and I suppose it was the start of some internal haemorrhaging. My mother sent for me and I arrived with GRO-B at the hospital just before 9pm. I had not been to visit my father that day and we were just about to leave the house for a night out (it was a Saturday).

27. I will regret those things for as long as I live. I remember my sister being at the hospital but don't know when she arrived or who with. I do know that she was unaware that my father was HIV positive and found out when the young doctor on duty that night, who was visibly very nervous, blurted out that my father had developed AIDS. The doctor of course assumed that everyone in the room was aware of his condition and I don't feel he did anything wrong. It was an awful way for my sister to find out though; she was still only 17 years old. My father was drifting in and out of consciousness when I arrived at the hospital but he did say hello to me so he knew I was there. The next 11 hours were the worst of my life. He was clearly in a lot of discomfort. His mouth looked very dry and I tried to moisten his lips with sponge swabs dipped into water. Blood was also starting to come from his nose. Eventually one of the nurses asked if we would like him to be given something to make him more comfortable. She warned us that he would not wake up again if he was given it. Without hesitation I said yes and my mother agreed. I would never have thought that I would be able to agree to such a thing but it was so awful to see him in so much pain and to know that he was not going to get any better.

28. He was given an injection and then he seemed to go into a deep and peaceful sleep. He died just after 8am the next morning. The cause of death on his death certificate, as well as being listed as Haemophilia and AIDS, was stated as being encephalopathy.

29. My father was a very private person who didn't even like to tell people that he had Haemophilia, so he definitely didn't want people to find out about his HIV diagnosis. The fact that we were unable to talk about his infection and illness put a strain on my mother and myself as well as my father. The stigma in those days meant you could not be sure how people would treat you if they found out. GRO-B

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GRO-B

30. I believe my father was made redundant from his job as an assistant in a [GRO-B] He already felt that because he was in his mid 50s he was unlikely to find work again as unemployment was very high at that time. When he was told that he was HIV positive he gave up looking for work completely. My mother was also a shop assistant who worked part-time in the evenings so that she could look after her young niece while her sister went to work in the daytime. This also caused my parents undue worry and stress as they were afraid that they might not be able to look after her anymore in case she was in danger of contracting the infection from my father. This would have broken their hearts as they both adored this little girl but after reassurance from my father's doctor they decided not to tell my Auntie of the situation and continued to look after my cousin.

31. To this day my Auntie and cousins still don't know what killed my father, my maternal grandparents were never told either. Indeed, my father and his 3 brothers and 1 sister did not discuss their statuses until my father's youngest brother became ill. Three of the four brothers, including my father, had haemophilia. Two of them had HIV (and I believe most likely Hep C also), the third brother was HIV negative but did contract Hep C and died in 1994. Their mother outlived them all, burying her youngest son in his late 40s and the other two in their 50s. After my father died I remember her asking desperately for reassurance that nothing would happen to her third Haemophiliac son. At the time nothing much was known about the Hep C infection so she was promised that this would not happen, yet just a few years later she had to suffer yet another loss.

32. My father was a great [GRO-B] FC fan and I think once he realised he was not going to have a son, he decided that he was going to try his utmost to turn me into as much of a fanatic as he was! He began taking me to reserve team home games at about the age of 11 and as I got older I graduated to first team matches. This continued until I was 20 years old when I met my future husband and started spending my weekends with him as he worked away

during the week. My father and I watched many memorable games together in the Kop at Anfield and also went to Wembley a number of times, including watching the FA Cup final between Liverpool and Everton. My father was lucky enough to get a season ticket in his latter years which was for a seat in the main stand. I began to realise how ill he was getting when I asked him one day what time he was leaving for the match and he told me with a worried laugh that he wasn't going.

33. Only since this Inquiry began have my sister, my mother and I begun to discuss what happened. We still don't really discuss it outside of our immediate families, mostly because there are still very few people that know. My two nephews were born with haemophilia and so we told my daughters about their grandad - who they sadly never met. I am not flattering myself when I say that I know I was the apple of my father's eye so I can only imagine how much he would have idolised my girls.

GRO-B

GRO-B

34. I have never felt able to tell my friends that I have known since school what happened to my father. Similarly, friends I have made since do not know. When the subject arises I dismiss it and change the conversation. At best they probably think that I'm very secretive, at worst they must think a complete weirdo.

35. I do not know whether my father faced any difficulties in obtaining treatment. When my father was diagnosed with HIV I believe there was only AZT available. I also recall that my father was taking Septrin, which was meant to protect him from getting pneumonia.

36. Being infected with HIV made it difficult for my father to receive dental care. His dentist would not treat him. He had to tell the dentist he was a haemophiliac and when the scandal came out the dentist refused to treat him. I don't believe that my father actually told his dentist of his infected status, but the dentist assumed that because he was a haemophiliac that he must be infected.

37. Even after this length of time it still all feels really surreal. It still feels like none of this really happened. I find it difficult to carry on with everything I do

GRO-B	after what happened to my father.	GRO-B
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GRO-B		I stopped eating for almost a month and lost over a stone. I don't know why it has taken this long to have an effect on me, but it has really hit home in recent months. I was totally distraught when my father passed away but I buried my head in the sand. In recent months I have had to talk about the reality of it all and it became too much for me.
GRO-B		GRO-B
GRO-B		I try to overcome the extreme anxiety I have been feeling.

38. I have also had to leave all the support groups on Facebook as I couldn't handle everyone talking about what happened. It became inescapable.

Section 6. Treatment/care/support

39. I do not believe my father faced any problems in obtaining treatment.

40. As far as I know neither my father nor my mum were offered any sort of professional counselling to help them deal with this terrible nightmare they found themselves living in. Neither my sister nor I were offered any professional emotional support either.

Section 7. Financial Assistance

41. My sister and I were over the age of 16 when my father died and therefore we were not taken into account when the ex-gratia payment was made to my mother. When my father was alive I know they received some money from the Macfarlane Trust to install a shower unit in their home as my father was beginning to struggle getting in and out of the bath. The ex-gratia payment was made too late for my father, he died before it was granted. My parents were never affluent anyway but once my father lost his job things were obviously more difficult financially. It would have been something less for him

to worry about if he had been compensated and I strongly agree with those campaigning for those infected and still alive to receive compensation as soon as possible.

42. I have never received anything from the Trusts and Funds that were set up.

Section 8. Other Issues

43. I have tried to obtain my father's medical records from a number of different sources but so far I have only had limited information from the National Haemophilia Centre in Manchester. I was told that both his GP records and hospital records were no longer available. I was then advised to contact the Haemophilia Centre at the RLH to see if they held any of his records. They told me that the records of all Haemophilia patients from that time should have been kept due to the circumstances but were not able to find any belonging to my father. Interestingly, they advised me to contact the hospital's legal team and make them aware that I required my father's medical records as part of this Inquiry. I have yet to do this but fully intend to do so.

44. I am appalled that this happened. Politicians, medics and manufacturers of FVIII know what happened. They still say there was no conclusive evidence, but they knew the risks of what was going to happen. FVIII should have been withdrawn as soon as they had knowledge of the infections. Had the people in charge had their families on the line this would never have happened.

45. Our politicians should have refused to import these products.

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Anonymity, disclosure and redaction

46. I wish to remain anonymous.

47. I do NOT want 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

29/3/2020