

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1335001

Exhibits: WITN1335002

Dated: June 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF **GRO-B**

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I, **GRO-B** will say as follows:-

#### Section 1. Introduction

1. My name is **GRO-B**. My date of birth is **GRO-B** and I live at **GRO-B**.
2. I make this statement on behalf of my late father, **GRO-B: F**. He was born on **GRO-B** and died on **GRO-B** aged **GRO-B** as a result of Cerebral Toxoplasmosis caused by HIV.
3. My mother, **GRO-B**, has also produced a witness statement **GRO-B** for the Inquiry.
4. I am married and I have a son, **GRO-B** who is a severe haemophiliac. I recently quit my job to go back to university to study **GRO-B**. I have been in the **GRO-B** for some time now and I used to work in the **GRO-B**.
5. In my **GRO-B** I found out I have a low clotting factor and I'm a symptomatic carrier. I was told by the doctors that if I was to have major surgery I should informed the doctors as I am more likely to bleed more.

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6. My son, [GRO-B] was born in [GRO-B] and he was diagnosed with severe Haemophilia A shortly after birth. As a result of his haemophilia the hospital requested to review my father's medical records to see what genotype my son would've had. We therefore applied for the medical records from the [GRO-B] [GRO-B] and we were told that there are no medical records and that my father was never a patient there. This was quite upsetting as my father was always treated at the [GRO-B] and he spent his last weeks at the hospital where he died.
7. For the reasons stated above, this witness statement has been prepared without the benefit of access to my late father's full medical records.

### **Section 2. How Affected**

8. I wish to rely on my mother's witness statement for this section, as I was very young when my father was diagnosed with HIV.
9. I recall my father having Factor VIII concentrate (FVIII) as he had a special fridge where he stored the blood products.
10. I found out when I was about [GRO-B] years old that my father died as a result of the infection. My mother then told me how my father was infected with HIV.

### **Section 3. Other Infections**

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

### **Section 4. Consent**

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

### **Section 5. Impact of the Infection**

13. I wish to rely on parts of my mother's witness statement in relation to this section.
14. I remember a couple of violent episodes with my father towards my mother when I was young. I remember my father waving a knife at her. This was

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completely out of character. It made sense when my mother told me about the infection when he started acting out of character. I don't have the best impression of my father, I have some good memories and then violent ones. I recall an incident when my mother was reading a story to me in my room and then suddenly my father came in waving a knife. He had random outbursts. I believe that things were bubbling up inside of him and the depression was manifesting itself in that way. I believe that because of my father's actions I started to have a phobia of knives. It was difficult seeing my father the way he was and the way he was treating my mother at the time. Everything that has happened in the past affects me more now.

15. I recall that we moved from [GRO-B] and we became very isolated from our extended family. They eventually moved down to [GRO-B] but at the time it was just the [GRO-B] of us living in [GRO-B] starting fresh, with no friends or family. I believe my mother and I were the closest people to him to take his frustration out on us.

16. After my father died, my mother met my step-father and they married. My step-father has been very good to me and always treated me as his own.

17. After my son was diagnosed with haemophilia and knowing that my father died from an infection that he received from the treatment that was supposed to help him, this always plays at the back of my mind when my son is being treated by the doctors. I always get reassurance from the doctors that the treatment my son is having is safe. However, it never stops me asking questions. I am very vigilant with what happens in the hospital in relation to my son. I think the doctors hate me because I question them all the time. I do not let the doctors take my son's blood for testing, I do it myself under the doctor's supervision. I document everything and every blood test in my diary. Back when the doctors were treating my father, the doctors were known as 'gods' and people trusted them and didn't question their advice. I am the total opposite because of what happened to my father.

18. What happened to my father has impacted the way I perceive things for my son. I have a lot of anger because before [GRO-B] started his prophylaxis, the

doctors needed to know [GRO-B] genotype. As previously stated we could not get my father's medical records, which would have assisted the doctors with my son's genotype. [GRO-B] was put on different treatments to see which treatment would work and as a result he has developed inhibitors to the treatment he receives now. I believe that had we had my father's medical records, we could have avoided it all.

19. In the last few weeks of my father's life, I went to [GRO-B] and stayed with my grandmother. I remember going to the hospital to visit him when he was dying. I don't remember when he died. A few years of my life has been wiped out of my memory.

20. When I later found out that my father died of HIV as a result of the FVIII blood products that he received, it made me angry. I was quite shocked and stunned by it. I was angry that my father was taken from me unnecessarily. I was scared that I couldn't even tell anyone about it because 1; I was told to keep it to myself and 2; I didn't feel comfortable telling anyone as I was worried about their reaction. At the time I couldn't tell even my best friends. When I got with my husband, I only told him after several years what happened to my father when we started talking about marriage and children. I also told him that I was a haemophilia carrier. I have never had these conversations with previous boyfriends. I kept it very private at the time.

21. I do recall the adverts about HIV at the time, it was quite harrowing and I believe this was the reason why people did not understanding the infection. It was portrayed by the media as an unknown infection that was spreading like wildfire. I believe it was a shock tactic to control the infection at the time.

#### **Section 6. Treatment/care/support**

22. I do not know if my father was offered any counselling or psychological support.

23. I had a psychological evaluation after my father's diagnosis which was arranged by my father's hematologist at the [GRO-B] when I was about [GRO-B] years old. I do not remember why I had it or if it was even related to my father's

infection. My mother told me that that it was quite random. They got me to do things and asked me questions to see how I responded. Now thinking about it there was no reason for me to have it as I had no medical conditions. There were no mental health issues in the family and I wasn't diagnosed as a haemophilia carrier until I was in my GRO-B I exhibit a copy of the report at 'WITN1335002'.

#### **Section 7. Financial Assistance**

24. I got an ex gratia payment from the Macfarlane Trust when I turned 18 as it was held in trust. I can't remember how much but it may have been just under £20,000.
25. The funds and trusts set up were clearly a con because you could have the money but you had to sign a waiver confirming that you would not make any further claims. Why would that be a stipulation if they had nothing to hide?

#### **Section 8. Other Issues**

26. It was very frustrating when we unable to get my father's medical records, not only for the purposes of the Inquiry, but for my son. To be told that he was never treated at GRO-B really upset me and made me angry.
27. I want answers to find out what exactly happened and someone needs to be held accountable for what happened.

#### **Anonymity, disclosure and redaction**

28. I wish to remain anonymous.
29. I do not want to give oral evidence to the Inquiry.

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## Statement of Truth

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

Signed

GRO-B

Dated 26/06/2019