

Witness Name: **GRO-B**

Statement No: WITN1449001

Exhibits: 0

Dated: FEBRUARY 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** 1980 and I live at **GRO-B**.
2. My father, **GRO-B: F** (born on **GRO-B** 1946) was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated blood products. My father died from heart failure on **GRO-B** **GRO-B** 1994, aged 47.
3. My mother has given her own Witness Statement to the Inquiry (Witness Number: **GRO-B**).
4. This Witness Statement has been prepared without the benefit of access to my father's medical records.

## **Section 2. How Affected**

5. My father had severe Haemophilia A, diagnosed in his childhood. I do not think that haemophilia ran in my father's family. I believe that he had a difficult childhood although he spoke very little about it to my sister and me. He was apparently sent away to a boarding school for children with disabilities in GRO-B He was not there long. The conditions at the school were awful and I believe him to have been traumatized by the experience.
6. My father was treated at the Nottingham Haemophilia Centre at the Queen's Medical Centre under the care of Dr French. When he found out that he had received contaminated blood products he transferred to the Sheffield Haemophilia Centre at the Royal Hallamshire Hospital, Sheffield.
7. My father treated himself with Factor VIII (FVIII) at home. My parents had been married previously and my father only started using FVIII after they began living together in the mid to late 1970s. I do not know what treatment he had before that. He had bad knee joints and would use the FVIII when he had a flare up. He played his haemophilia down but my sister and I knew when he had a flare up because he needed to use walking sticks. We knew that without FVIII, he could bleed to death. It was hailed as the miracle drug that revolutionised lives.
8. I was 9 or 10 years old when I found out that my father had HIV. I found an opened letter saying something about HIV and I said to my sister "I think something is wrong with Dad. I don't think Dad is very well". My sister responded "Don't you not know? ....." My sister was just under two years older than me.
9. I suspected that something was very wrong before then. My father was an Accountant. He had a 45 minute commute to and from work and did not get home until after 7.00 pm during the week. My mother worked too. She took us to school and picked us up from our childminder in the evenings. There was little family time for us during the week but in retrospect I was aware of

the tension between my parents within the household. They must have been under a terrible strain.

10. I do not believe that my father was given any information or advice about the possible risk of infection before he was treated with FVIII. My father never did anything risky. No-one at that time thought you could become infected through blood products. I understand that my father was told that he had HIV after we returned from a two week holiday in Cornwall. My mother has described to be that he was furious. It was so unlike him to do that. He was ordinarily so calm and measured. I also picked up on snippets of conversation between my parents that I had not fully understood or appreciated. If my father had been warned of the risk, I do not believe he would have reacted like that. He was a rational, methodical, pragmatic person.
11. My parents had both been married previously and they lived together before their divorces came through. They would have been thought to be 'living in sin' at that time by small minded people. My sister and I were brought up with a clear understanding that no-one in our household aired their dirty laundry in public. I remember with clarity the tombstone advert and the associated stigma of HIV/AIDS. It was terrifying. I knew people with HIV/AIDS were treated badly so we did not talk about it. We did not discuss my father's HIV status openly and never outside the family.
12. I did not realise my father had HCV until he passed away. My father was diagnosed with HIV first and they did not disclose his HCV status to him straight away. The predominate thing was the HIV. I am not sure what he was told about HCV. My parents asked about HCV and had to push for testing in or around 1987.
13. I remember being told not to use my father's toothbrush. He had a Sharps bin (a yellow medicine bin to dispose of used needles and the like) and I was told not to go anywhere near it. It was a very serious rule of the house.

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

14. I do not believe my father received any other infection that HIV and HCV.

### **Section 4. Consent**

15. Consent does not mean the same thing today as it did back then. I am unable to comment as to whether my father was given full and adequate information to provide his full consent to tests and treatment.

16. I understand that my father had deep concerns about HIV/AIDS after watching a documentary type television programme with my mother. My father apparently called the Nottingham Haemophilia Centre to ask if he should be worried and they said 'oh no do not worry'. My father had to do all the chasing for reliable information and eventually they tested him but only after he asked several times. He felt duped by the experience.

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

17. My father passed away three weeks after my 14<sup>th</sup> birthday. He was admitted to hospital in December 1993 (the year before his death) with an AIDS related virus and was there for a few weeks. I did not fully appreciate the gravity of my father's condition and how close he was to death. I had a number of visits with him but I was shielded from the truth. He had a lumbar puncture to ascertain what it was and the test came back as inconclusive. The doctors were at a loss as to how to best treat him.

18. My mother was keen for my father not to spend Christmas in hospital and she was relieved when the hospital said he was able to come home for a few days. I believe that she was warned that my father would not be able to combat another viral attack. My sister and I were not told.

19. My parents owned a narrow boat moored up 20 to 30 miles away. Dad spent a lot of time on the boat fixing it up and kitting it out. He became more and more distant and reclusive in the months before he died. In retrospect I believe he was hiding himself away, preparing himself and us for when he would not be around. My father was on the boat the (bank holiday) weekend that he died. My father's work phoned and alerted us to the fact that my father had not turned up for work after the weekend. We were worried and I phoned him several times. When someone finally answered it was not my father and I said "oh sorry, wrong number". I was asked if I was David's wife and I passed the phone to my mother and sat down on the stairs to listen to their conversation. I remember my mother turning to me and saying "your Dad is dead". The doors and the opening hatch to the boat had been left open all night and someone had thought that odd and found him.

20. I was heart broken. His death made no sense to me. My only experience of death had been that of my grandad's death, in a hospital bed with his family around him waiting for it to happen. My father looked well and had hidden the full extent of his failing health from me. He was always thin in stature and was olive skinned. He had marks/legions predominantly on the back of his hands but they could be explained away as age spots or liver spots.

21. I believe my father's Death Certificate records heart failure as the cause of death. This was at a time when no-one put HIV/AIDS or any related illnesses on death certificates if at all possible for sensitive reasons and so that life assurance policies and the like would pay out. I believe the accumulative affects of the combination of HIV and HCV actually killed him. Both conditions are known to increase the risk of heart disease.

22. I was only 14 years old when my father passed away. I was only just learning to view him as a person in his own right, with thoughts, feelings and views that are independent to just being a father. We were never able to sit down together and talk about his illness. It was just something he had to deal with on his own. The first funeral that I ever attended was my father's. It was

surreal. If I had six months or even six hours with my father now, I would make the most of every minute of it. I thought my father was invincible. I still feel the pain of his loss. I have spent the last 25 years trying to put myself back together again.

23. My father's contamination and subsequent death has affected so many aspects of my life. My education suffered and I could not stick at anything. I was predicted 'A's and 'A\*'s at GCSE and got 'B's and 'C's. I dropped out of my A-levels and tried to gain a B-Tec qualification but I could not focus. There was tension in the household and a lot of unresolved anger. We were so angry and upset that we turned on each other. Our family fell apart. My relationship with my mother broke down. We still suffer to this day. I have racked up credit card debt. I have been through therapy and am now, all these years later, back in education, at university pursuing a degree (as a mature student) in set design.

24. My sister has been badly affected. She has a two and a half year old daughter. My father never got to walk his daughter down the aisle or to meet and spend time with his granddaughter.

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

25. My father had AZT treatment for HIV. I remember my father saying that the mere fact that he had to take tablets to treat HIV were a daily reminder that he was dying. I cannot imagine the extent of the impact on my father mentally and emotionally of knowing that you are dying. Everyone has questions about their own mortality but it profoundly changes you when you know you have something that is killing you. I do not know if my father had treatment for HCV.

26. I do not know if my father was offered counselling. I do not know if he took it up and/or if it was helpful to him.

27. I went to speak to some shortly after my father was diagnosed with HIV. After my father was diagnosed, I remember having a counselling session with a lady but I did not understand the purpose at that time. I have had a lot of counselling over the last twenty years as my mental health has been seriously impacted. My state of mind has been shocking.

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

28. I am not sure about the precise nature of the payments my parents received from the various Trusts. I know that there was a payment that my father received before he died. He was told that he had to sign it or he would not get anything. I believe him to have been bullied into it.

29. My mother had told me that one of the Trusts told her that she did not qualify for a specific payment because of the cause of death (heart attack) recorded on his Death Certificate. As stated, I believe that the HIV and HCV infections caused my father's death. He was very clearly unwell. Even if he had been hit by a bus, it would not change the fact that he was infected from contaminated blood products.

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

31. There are no other issues.

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

31. I do not want to give oral evidence and I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry.

**Statement of Truth**

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

Signed GRO-B .....

Dated 27- feb - 19 .