

# ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN1747001

Exhibits: 0

Dated: October 2022

## 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** I was born on **GRO-B** and I live at **GRO-B** with my wife and three sons.
2. My father, **GRO-B: F** (born on **GRO-B** was co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) through contaminated blood products. He died on **GRO-B** aged 54.
3. I am one of three siblings. My sisters, **GRO-B** and **GRO-B** have also provided witness statements to the Inquiry, **GRO-B** and **GRO-B** respectively.
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 Dad had severe Haemophilia A. Dad was under the care of Dr Christine Lee at the Royal Free Hospital (RFH) in London. He was treated with Factor VIII (FVIII) concentrate from some time in or around the mid-1970s. He was given the FVIII concentrate as a home treatment to use as and when he had a bleed. He always made sure that he had a good supply of it when we went on holiday.
6. I do not think that Dad was given any advice or information beforehand about the risk involved with FVIII blood products he was using. My mother remembers contacting the hospital after hearing concerning news about haemophiliacs being infected with HIV.
7. My parents were told that Dad was infected with HIV at a routine appointment in 1982 or 1983.
8. I believe that the information about risk should have been provided to my father earlier and I believe that the doctors would or should have known that the blood was from a dubious origin. My parents trusted the doctors at the RFH – they had to. I was 12 years old when our parents told us that Dad was infected with HIV. I do not know what information or advice he was given to help him understand or manage the infection, but looking back it was clearly inadequate. The psychological impact on him was catastrophic. As a haemophiliac needing ongoing care, he seemed powerless to challenge the doctors looking after him and/or risk rocking the boat by asking too many questions.

## **Section 3. Other Infections**

9. Dad developed Vasculitis through being infected with HIV, HCV or a combination of the two.

**Section 4. Consent**

10. I believe that Dad was treated and tested without his knowledge, without his consent and without being given adequate or full information.
11. I do not know if he was also tested for the purposes of research.

**Section 5. Impact of the Infection**

12. Dad suffered with significant mental and physical effects from various infections he developed as HIV turned into full blown AIDS.
13. There was no cure. No treatment was available to Dad. Dad knew he wouldn't see his way through it. My overriding memory in the early years was the never-ending three-month cycle of dread we endured. Dad had visits to the RFH every three months to check his CD4 levels. I remember the heightened state of anxiety we felt leading up to the appointment, the relief when we heard the news was OK and then the worry again as the proximity of the next appointment drew closer.
14. Amazingly, Mum and Dad navigated me and my sisters through it all in an open way. The upside to it was that we were part of it, and we could understand what was going on, but the downside to it was that we too were entrenched with the fear and misery of Dad's situation. We could talk about it within the household, but outside the walls of the house 'no', we told no-one. The fear and stigma were terrible. It gripped the nation. I lived a double life. We had an opinionated biology teacher at school who pretty much said 'people who have this (HIV/AIDS) are a danger to society and should be rounded up'.
15. The stigma definitely affected us all as a family. If you have cancer, you can expect sympathy and understanding from others but that was not the case with HIV/AIDS. My parents had to be incredibly selective with who they told. There was a part of our family existence that was very much behind closed doors, but,

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in the main, my parents facilitated a normal upbringing for me culminating in me going to university and enjoying that time away from home.

16. My overriding memories of Dad's latter years are characterised by his failing health. Most upsettingly, his character changed over the course of his illness. It's impact on him was ghastly. It sucked his very being away from him. Dad was a deep thinker, and he became very depressed. My parents weren't drinkers, but I remember Dad glugging down two bottles of wine in succession and throwing up. He and Mum met at aged 14. They were childhood sweethearts. Their relationship became hugely strained as Dad was hard to deal with when the illness affected his brain. Dad's brain became mangled through his illness. He had a brain scan which showed damage to a large part of the frontal lobe. In the last two years of his life, he was not the man he was or wanted to be. Dad had horrendous bed sores. He lost large parts of his vision and he was almost blind when he died. I remember him telling me just what an amazing thing it is to be able to see and that I should never take my eyesight for granted.
17. Because of his haemophilia, Dad was physically disabled, and he could be quite morose at times. I was very physically able, and we never really connected. We had just started to connect during my university years, but then Dad's health went downhill and then he died. I am good at burying my head and getting on with life but the feeling of sadness about that gets worse as time goes by. He and I would have got along well and that is what hurts the most; we never had the opportunity to be mates. The time I needed to grow up was taken and with it, the chance to have a fulfilling relationship with him.
18. What happened to Dad has created huge fractures between my mum and my sisters that wouldn't have otherwise been there. There is a very negative imbalance in our immediate family relationships that wouldn't be there if he was still alive – there has been a terrible additional cost that we're still paying the price of today. That was contributory factor in me moving from the UK with my family. I needed to get away from the way things were. Mum still misses Dad

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terribly. Dad never met my children. There is no start and finish to any of these traumatic events. **My reality is that it is harder not easier as time goes by. The longer I live, the sadder it all gets.**

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

19. I do not know what treatment Dad was offered (if any). Dad was not provided with any support as far as I am aware. I was never offered counselling or psychological support.

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

20. I believe my father was in contact with the Macfarlane Trust and received some financial assistance.

21. In terms of financial assistance given verses the loss of earnings Dad suffered through being unable to work, the financial assistance was insufficient. It added a lot more stress and pressure to my mother at a time when she was already struggling to cope

### **Anonymity, disclosure and redactions**

22. I wish to remain anonymous and I understand that this redacted Statement will be published by the Inquiry. I do want to give oral evidence to the Inquiry.

### **Statement of Truth**

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

GRO-B

Signed...

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Dated...25/10/22.....