

Witness Name: GRO-B

Statement No: WITN5268001

Exhibits: 0

Dated: January 2021

## 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.  
GRO-B
2. My father, GRO-B: F (born on GRO-B), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated Factor VIII (FVIII). He died on GRO-B, aged GRO-B.
3. This witness statement has been prepared without the benefit of access to my father's full medical records.

### Section 2. How Affected

4. My father (Dad) had severe Haemophilia A, diagnosed at birth. He was under the care of Professor Hay at the Haemophilia Centre at the Manchester Royal

# ANONYMOUS

Infirmery (MRI). He was, I believe, treated with Cryoprecipitate initially and then with Factor VIII (FVIII) concentrate.

5. I did not know that Dad was co-infected with HIV as well as HCV until just over a year ago. I knew that he had HCV. As a teenager, I once found came across a letter from the Skipton Fund and I asked my Grandma about it, as my Dad's only comment was 'Cos they owe it to me'. Dad didn't want to talk about being infected with HCV except to sometimes say things about his poor health I didn't fully understand like '*They* did this to me'. He was under the care of Dr Prince, Consultant Hepatologist at the MRI.
6. My Dad was living at home with my Grandma and my Aunt when he found out that he had tested positive for HIV in the 1980s and they were the only two family members that knew. I do not think my own mother knew about it.
7. My Dad didn't want anyone to find out that he had HIV and kept his antiviral medication at my Grandma's house. When she died in 2016, he then kept his medication at my Aunt's house.
8. Before the Covid-19 lockdown in March last year, Dad would make us (me and my sister) sit down during visits and watch the oral evidence of those infected and affected at the Infected Blood Inquiry on TV. It was bad enough to listen to the experience of others infected with HCV, but it came as a shock to us when Dad told us that he was amongst those also infected with HIV. He told us that we had to fight for him if he died.

## **Section 3. Other Infections**

9. Dad was also advised that he might be infected with vCJD, but it was never confirmed. He called it 'Mad Cow Disease'.

#### **Section 4. Consent**

10. I believe Dad was treated and tested without consent and without adequate information. He believed that he had been used for the purposes of research. He said several times that he was used as a 'guinea pig' and that he felt like a 'leper'.

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

11. Dad was deeply affected psychologically and emotionally. He would stay up all night, crying. He would keep us up all night too if he could, telling us stories we thought were about others at the Inquiry on TV. He wanted to protect us by keeping it from us for so long, and it hurts me that he didn't confide in us sooner as he needed someone to confide in and he didn't want to be alone. It was a big weight lifted from him when he finally told us. He had been frightened that we would be bullied and stigmatised if it came out sooner.

12. After staying up all night, Dad was then left exhausted during the day. He used to get up in the afternoon (sometimes not until around tea-time) and watch the TV, the horse racing and, latterly of course, the Inquiry. He couldn't live the life he deserved to live. He liked his pint of John Smith's and would drink to cope.

13. Dad was always quite secretive about money through a bad experience he had after telling two friends that he was infected with HIV when he was young. Dad left home and lived with my Mum in a house he bought before I was born. His friends broke in and robbed his house and stole from him. I found out relatively recently that they not only knew that he had HIV, but they also knew about the £50,000 payment he received through the MacFarlane Trust.

14. Dad was scared to travel in case something happened to him. He couldn't get life insurance. He needed a knee. He had to pull his own teeth through

lack of a dentist to treat him and a hairdresser wouldn't even cut his hair. So much more could and should have been done for him. He shouldn't have had to live like that.

15. It was a worry for Dad when my sister and I were each pregnant (my sister at the age of 18, and me at the age of 17). We had to see Dr Hay and have tests at the MRI through the uncertainty of whether we were carrying boys with haemophilia. I remember Dr Hay saying 'all bloods are clean now', which, back then, didn't make a lot of sense to me. Dad had quite a few quiet/private conversations with Dr Hay at that time and we weren't included. My sister and I were also tested for HIV. I didn't know that was unusual. When my son was born, I remember Dad and my Grandma both crying with relief after it was confirmed that he was free from haemophilia.

16. Dad had so many serious health issues through having HCV (and HIV). He had Cirrhosis, Portal Hypertension and Pulmonary Hypertension.

17. Dad would bleed out from both ends. My sister and I saw him bleed out twice. We found him comatose on one occasion and he was hospitalised with just half a pint of blood left in his body and very close to death. I was always scared Dad was going to die even though I didn't even know the full extent of all his medical problems. I wanted him to have a liver transplant. He was infected through no fault of his own and he should have been prioritised for a liver.

18. My Dad used to drink, preferring people thought of him as an alcoholic rather than a haemophiliac with HIV. He hated everything about haemophilia. It ruined his life. He even told Mum when they first met that he was a drug addict to explain his use of needles. Dad chose to drink but was not alcohol dependent. He could give it up in a blink of any eye. He gave up for six months before his death and had never looked better.

19. Dad was bleeding from the ear for a while and fell down the stairs and haemorrhaged before his death. He had not seen his GP about the bleeding ear because of the risk of catching Covid19 at the surgery. His death came as a terrible shock to us. The cause of Dad's death was multiple organ failure, predominantly liver although no autopsy was performed. I am so angry that more wasn't done for him. To make matters worse, we were told that Dad's body was infectious, and I wasn't allowed to visit him at the funeral home. We weren't even allowed to dress him (my Aunt tried to take his clothes up) and they wouldn't open the coffin.

20. This tragedy has ruined our family. The loss of my Dad is massive for me and my son and daughter. It has ripped the family apart and left our mental wellbeing (and particular my sister's) in tatters. My Dad was such a wonderful man.

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

21. Dad had treatment and was told that he had cleared HCV the year before he died.

22. I don't think Dad was ever given any counselling or support. He would just sleep all day and stay up all night crying. He was scared and had no support to help him to deal with this way of living.

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

23. Dad received payments from the MacFarlane Trust and from the Skipton Fund. My sister and I were offered some funding for the purpose of counselling, but we did not accept it.

**Anonymity**

24. I do wish to remain anonymous and I understand that this redacted Statement will be disclosed for publication to the Inquiry.

**Statement of Truth**

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

Signed..... GRO-B .....

Dated.....26/01/2021.....'