

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN3201001

Exhibits: WITN3202002 – WITN3202004

Dated: October 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** and I was born on **GRO-B** 1937. My address is **GRO-B**
GRO-B

2. My brother, **GRO-B: B** contracted HIV through being given contaminated blood products and passed away in 1989 as a result, at 58 years of age. I am providing this statement to the Inquiry to discuss the impact that this has had on me and my family.

Section 2: How Affected

3. **B** was born in 1931 in London. Haemophilia was not a well-known condition at the time. However, I understand that **B** was diagnosed with severe haemophilia A during his childhood and that he had a very disrupted education due to this condition.

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4. There was no treatment for haemophilia during **B** childhood and, if he suffered a bleed, he would simply be told to rest at home in order to recover. When World War II started in 1939, everyone's focus was on just surviving the war rather than particular treatment needs. During this period **B** was under the care of the North Middlesex Hospital ("North Middlesex"). He was actually at North Middlesex when **GRO-B**

GRO-B

GRO-B

5. Throughout this period **B** spent a lot of time away from school because he would be resting at home to recover from a bleed. I recall that the school used to send books home to **B** and he effectively taught himself to read and write at home. **B** eventually left school at the age of 14 in 1945.

6. Following school **B** became employed as a factory worker. The nature of the job was such that **B** found it very difficult, and he ended up having to leave this job. He was then fortunate enough to secure employment **GRO-B**
GRO-B when he could. **B** also liked to get out and cycle when physically able, but life for him basically consisted of a lot of bed rest and hospital visits.

7. Unfortunately, in 1954 when **B** was in his early twenties he suffered from a mental breakdown. This happened soon after seeing Dr Macfarlane at the **GRO-B**
GRO-B He had been invited to see this doctor but we did not learn what had happened. I assume **B** was hoping to hear of a treatment or some alleviation from suffering, but there was no such treatment yet for haemophilia at that time. His behaviour became increasingly erratic leading up to an attempted suicide with sleeping pills. A stomach pump treatment saved his life. Following this event, we all had to be watchful for any further mishaps.

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8. I moved out of the family home in London to study at GRO-B University in 1957. Whilst I was not at home much during this period as a student, B was diagnosed with schizophrenia and taken into GRO-B hospital. He was given electric shock treatment for the schizophrenia. B mental health never recovered in my view and he did not communicate with the family or with people in general.
9. I got married in GRO-B and was employed as a GRO-B. I moved around with my husband for a while before settling in GRO-B in the early 1970s. My father died in 1969, which left my mother as the sole carer for B. As such, my husband and I invited my mother and B to come and live with us in GRO-B GRO-B.
10. We used to take my mother and B on holiday within the United Kingdom at least once a year and would get B out of the house when we could. He was unable to participate in physical activities so, with my mother and our two children we went everywhere in the car. I recall one holiday in the Cotswolds where we did a lot of walking. B would always try and do everything he saw the rest of us doing and would never complain about being tired, but this particular holiday in the Cotswolds really took a lot out of him.
11. When B moved to live with us in GRO-B his care was transferred to Leicester Royal Infirmary ("Leicester Royal"). Sister Martin, a haemophilia nurse, would regularly visit B and check up on his condition. He continued to have bleeds and various emergencies during this period. I do not recall what treatment B received from around 1970 to 1982 but he had regular visits from Sister Martin, hospital appointments and a lot of bed rest following any bleeds.
12. In 1982 B suffered significant bleeds from a stomach ulcer and was admitted to Leicester Royal. I remember visiting B in hospital where he told me he thought he was going to die. Communication like this was unusual. Whilst I cannot

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be certain, because the hospital lost his medical records, I believe [B] was given Factor VIII for the treatment of the ulcers because of his sudden recovery after being so weak and ill.

13. I do not recall the doctors ever confirming to me or my mother that [B] was being given Factor VIII for his treatment and he still did not communicate normally with us.

14. In around 1983 [B] required some dental work (including teeth extractions) which meant that he would need Factor VIII to stop any bleeding. The local dentist would not have been supplied with Factor VIII in order to carry out this specialised work of operating on a haemophiliac. As a result [B] was referred to Leicester Royal where the dental work was undertaken. [B] never complained about this treatment and I assume it was a success. I do not know if he was given any Factor VIII as part of the procedure, but it is most likely because of the usual bleeding from tooth extractions, making Factor VIII essential.

15. As a regular patient at Leicester Royal I am sure [B] would have been tested for HIV. In summer 1984, Sister Martin came to see my mother and myself to confirm that [B] had contracted HIV. There was no explanation of how [B] had contracted HIV. Sister Martin asked us whether or not she should inform [B] and we decided it would be better for him not to be frightened about this.

16. Everything had to carry on as normal except we had to keep very quiet about this as HIV was being broadcast to the public as the next plague. From 1984 to 1988 I recall [B] was still regularly going to hospital. I am not sure if he was treated with Factor VIII during this period, or whether he had any home treatment. I know that my mother and I did not administer any Factor VIII treatment, but I cannot be sure whether or not Sister Martin administered any treatment during her visits to see [B]

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17. In around 1988, my mother and [B] moved from our family home into a maisonette. My mother wanted her independence again after living in our shared home for eighteen years. Consequently, we purchased a maisonette for her and [B] to live in. [B] health deteriorated and he was really struggling with his breathing in the last year of his life and he spent most of the time in bed in the maisonette.

18. As mentioned above, [B] passed away in 1989 at home. His death certificate confirms the cause(s) of death as: 1/a: pneumococcal pneumonia, 1/b: HIV, 1/c: infected factor VIII transfusion and 2: Haemophilia A. I do not recall any discussions about [B] funeral arrangements after he passed away.

Section 3: Other Infections

19. I am not aware if [B] was infected with any other viruses as a result of being treated with contaminated blood products. I am aware, however, that what is now known to be Hepatitis C was not connected to contaminated blood products until around 1991 – around two years after [B] passed away. I do not know if he was ever diagnosed with Non-A Non-B Hepatitis as it was known before the 1990's.

20. I tried to obtain [B] hospital records to support our application to the Skipton Fund, however I was advised his records had been destroyed when Groby Road Hospital closed down [Exhibit WITN3202002].

Section 4: Consent

21. I am not aware whether or not [B] consent was obtained before he was tested for any viruses linked with contaminated blood products.

Section 5: Impact

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22. The manner of [B] illness and death had been a very traumatic experience for my family. When we were told in 1984 that [B] had contracted HIV it was extremely frightening given that there was a lot of panic caused by the media and nobody at the time knew how the virus could be transmitted. As a family, we decided not tell anybody about [B] having contracted HIV. I remember telling my son, but did not tell my daughter at the time.

23. I was deeply affected by [B] having contracted HIV. It left me severely depressed and I ended up leaving my job. I recall having to watch [B] health deteriorate and him really struggling to breathe. I remember one appointment at Groby Road Hospital when [B] was given treatment with a mist inhaler to help him breathe easily. It caused him great stress and panic as he was not able to catch his breath. Mother and I were asked by the doctor in charge of this treatment whether we wished [B] to have further treatment. After consideration, we both agreed he had suffered enough and thought that he was not a suitable subject for experimental treatment.

24. My mother passed away in 1998. She was always bitter that nobody acknowledged or apologised for the contaminated blood scandal. The impact of [B] contracting HIV affected her deeply and she felt very strongly against telling anyone about [B] having contracted HIV because of the stigma at the time. We only very recently told the rest of our family about [B] having contracted HIV through contaminated blood products.

Section 6: Treatment/Care/Support

25. [B] was not offered any support after contracting HIV. As far as I am aware, [B] was not aware that he had contracted HIV before he passed away.

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26. My family and I were not offered any support, nor did we expect it. At the time we were told that [B] had contracted HIV, nobody knew what to do and there was no treatment.

Section 7: Financial Assistance

27. At the time of [B] death in 1989, we did not know much about the HIV or Hepatitis C infections. In the early 1990s, after [B] had passed away, my mother received money which came from the Macfarlane Trust. This enabled her to repay us for the purchase of the maisonette.

28. In January 2011, as [B] closest living relative, I was advised by The Haemophilia Society to apply to the Skipton Fund for financial assistance following the contaminated blood scandal [Exhibit WITN3202003]. I did follow their advice and made the application which was approved [Exhibit WITN3202004]. We received £20,000 in June 2011.

Section 8: Additional Information

29. One other thing that has troubled me is that my GP (in [GRO-B] in the 1960s) did not advise me or suggest that there was any possibility of having a haemophilic baby when we were starting a family. The indication was that [B] condition was a "one-off". The advice in the 1960s was very different from today.

30. My daughter [GRO-B] is also a carrier of haemophilia. Her son (my grandson), [GRO-B] was born in 1994 and was diagnosed with severe haemophilia A. This was very distressing not only on his own account but it also brought back the memory of how [B] had suffered disappointment, frustration and pain throughout his life.

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31. I believe **GRO-B** has only ever been given Recombinant Factor VIII. On the first day of university, following a prank on fresher's week, he got injured and ended up on crutches. Dan eventually ended up leaving university after two years because of an increasing problem with arthritic ankles and he struggled with his haemophilia during this period and also depression. Due to prophylaxis with Factor VIII **GRO-B** has suffered fewer bleeds than my brother so his educational and social experiences were very different from my brother's.

32. **GRO-B** has had to have two ankle operations to fuse his ankle bones as a result of joint bleeds due to haemophilia. He also had to have counselling for the depression which ensued. He has since recovered from the depression and is waiting for the ankles to heal fully so that he can walk normally again and try to plan his future.

33. Given the impact that **B** suffering has had on me and my family, I would really like the Inquiry to provide answers as to how the contaminated blood scandal happened and who was responsible for it.

Statement of Truth

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

Signed **GRO-B**

Dated 29th October 2019.