

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN3136001

Exhibits: WITN3136002 – WITN3136004

Dated: 29 February 2020

Infected Blood Inquiry

WRITTEN STATEMENT OF **GRO-B**

GRO-B will say as follows:

Section 1: Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** 1967 and my address is **GRO-B**
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2. I am married and have two daughters aged 16 and 20 years old. I currently work as a Cover Supervisor in a Secondary School.

Section 2: How Affected

3. My parents had eight children, six boys and two girls. Five of the boys were haemophiliacs, having been diagnosed at a young age after being admitted to hospital at various different times. I am the youngest child and a carrier of the haemophilia gene. My other brother has not been diagnosed as having haemophilia, and my other sister is not a carrier. As far as I am aware no other generations of my family have been diagnosed with the same condition, either prior to or since the birth of my brothers.

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4. Two of my siblings died at a young age and I understand the causes of death to be related to bleeding and swelling of the brain. They were diagnosed with haemophilia.
5. My other three brothers were infected by contaminated blood products and all sadly passed away in the early 1990's. Their details are as follows:
 - a. **GRO-B; Brother 1** born on **GRO-B** 1953 and died on **GRO-B** 1993;
 - b. **GRO-B; Brother 2** born on **GRO-B** 1955 and died on **GRO-B** 1994; and
 - c. **GRO-B; Brother 3** born on **GRO-B** 1960 and died on **GRO-B** 1992.
6. From an early age I can recall **B1, 2, 3** injecting Factor VIII blood products at home on a daily basis. I cannot recall the blood product they all injected but assume it to be Cryoprecipitate. I would help them treat themselves, as would other family members. The boys were all diagnosed with severe haemophilia A.
7. Before they were able to self-treat at home, my brothers would go to St Mary's Hospital in Paddington on the bus. These journeys caused irreversible damage to their joints.
8. When the boys began self-treating, boxes of blood products were delivered to our home address, labelled from the USA. I think the boys did suspect that there would be negative health implications from the use of American products in later life. I recall hearing **B3** make a comment that "things were going to end bad" or words to that effect. However, there was no other alternative offered by doctors.
9. **B3** injected blood products with the least frequency and was more physically able than **B1** and **B2**. In particular, **B1** had contracted polio at a young age and so had a permanent physical disability.
10. They injected blood products daily over the course of ten years. **B3** went to Treloar College so he was injected with blood products (likely to be Factor

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VIII) whilst at school. **B1** and **B2** were home schooled and so their treatment happened at home most of the time too.

11. As far as I am aware, my parents were not told of the risks of treatment with Cryoprecipitate or any blood products.
12. By 1987, my brothers were all aware that they had contracted HIV. I do not know when or how they each found this out. Their HIV then developed into AIDS.

Section 3: Consent and Other Infections

13. I am not aware when or where my brothers were tested for the HIV virus or for any other purposes, and if they had consented to such tests being undertaken.
14. I am not aware whether they had any other infections.

Section 4: Impact

15. As a family we did not discuss the fact that **B1, 2, 3** had AIDS for fear of the stigma or reprisal outside the family home. The media coverage of AIDS in the 1980s was appalling. We lived on a Council estate and would often worry about finding graffiti on our door about AIDS or being subject to verbal abuse and vandalism. Thankfully this did not occur. We were respected. The neighbours were aware that **B1, 2, 3** had haemophilia and they were understanding, but we did not openly acknowledge that they had HIV or AIDS.
16. In 1984, my mother was diagnosed with cancer and she sadly passed away in 1987. My mother was strong and the matriarch of the family. She did not like asking for help from Social Services as she was too proud to do so. As a family we were self-sufficient but lived in a small house and had limited financial means. My mother died without knowing that my brothers had been diagnosed

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with HIV but she had seen the negative media coverage associated with the disease at the time and my brothers felt that had she known about their condition, this would have affected her badly.

17. My father knew that [B1, 2, 3] had been diagnosed with HIV, which later developed into AIDS. My father's coping mechanism was to drink alcohol. [B1, 2, 3] would often drink too.
18. At the time of my brothers' diagnosis, there was little information about the treatment of HIV or AIDS. We were told it was like a death sentence. There was the added concern that others in the family could have contracted an infection because we used to help the boys to inject blood products and shared drinks with them. Our concerns were not alleviated by medical professionals.
19. I was tested for HIV at a clinic before [B3] died so that I could stop worrying. Every time I was unwell I would think I was dying, which caused ongoing stress and anxiety. My sister has not been tested, however she has had children so assumes that she did not contract the virus as it would have become evident when she was monitored during her pregnancy, and then when her children were born.

Impact on [B3]

20. [B3] was determined to live his life as normally as possible and had a managerial job working at [B3]. He continued to work at [B3] until he got an infection in his foot, sometime in 1991 or 1992.
21. Prior to my mother's death, in or around 1987, I found a letter in [B2] bedroom from a solicitor about making sure his affairs were in order because he had tested positive for HIV, which later developed into AIDS.
22. [B3] was engaged to his partner around the time he found out he had HIV. He and his fiancée split up (I do not think this was because of his illness) and she married [B3] friend. Sometime afterward, she fell pregnant and gave

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birth to a baby boy. Within nine months, the baby died and then a little later, his mother did as well. Both had been diagnosed with HIV. It was assumed that she had contracted the HIV virus from [B3] although this was never confirmed. We never spoke about the cause of her death to [B3]

23. I cannot recall the date but sometime in 1991 or 1992 [B3] got an infection in his foot, which then became swollen. He was taken to Nuffield Orthopaedic Centre in Oxford and he was prescribed with antibiotics. A doctor chose not to drain the ankle of fluid, I think, because she or he thought it may affect the antibiotics working. Due to the pressure, his ankle/foot ruptured causing damage to the bottom of his foot. After that incident, [B3] deteriorated quickly. He frequently had thrush in his mouth, could not eat properly and was sick all the time, which meant he lost weight rapidly. It was assumed that his body went into septic shock and he did not recover from this.
24. [B3] married his girlfriend at the time, [GRO-B: B3W] three weeks before he died. [B3W] was later diagnosed with HIV, unbeknown to her parents, having been cross-infected by [B3]
25. [B3W] continues to manage her condition by taking medication daily. She suffered with severe depression and had psychiatric treatment for this. Unfortunately, [B3W] has not had children and has remained single since [B3] death. [B3] and [B3W] did ask a doctor about the prospects of having children but the response was negative and unhelpful.
26. [B3W] is on medication to control HIV but the stigma continues to negatively affect her. She has decided not to disclose her condition to her family. She was not able to claim for a widow's pension because [B3] was too young at the time of his death for her to qualify, but she does receive a monthly sum from a private pension.

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27. I exhibit a copy of his death certificate at WITN3136002 which confirms his cause of death as 1a) disseminated mycobacterium avium – intracellulare and 2) haemophilia.

Impact on **B1**

28. Like **B3** **B1** lived independently in a specially adapted bungalow, not far from the family home. When my mother was alive she visited him daily. He was funny, kind and had many friends. He did like to drink alcohol.

29. As a child, his friends did not treat him differently and they continued to be supportive in adulthood. I cannot comment on whether he discussed that he had HIV and then AIDS with his friends but assume that he did not, because the family as a whole had decided not to talk about it.

30. I exhibit a copy of his death certificate at WITN3136003 which confirms his cause of death as 1a) pneumonia and 2) haemophilia A.

Impact on **B2**

31. **B2** lived with our father in the home we all grew up in. After our mother died, my father cared for **B2** and they had a close relationship.

32. **B2** had a passion for horseracing and would go to the races often. Due to his having AIDS, he often experienced embarrassing and debilitating symptoms such as thrush, diarrhoea and piles, which were evident at home and outside the house.

33. When **B2** was unwell, he refused to be taken to hospital in an ambulance and instead I took him in my car. The trips to hospital were frequent, often twice a week and **B2** did not want to raise suspicion with the neighbours.

34. I exhibit a copy of his death certificate at WITN3136004 which confirms his cause of death as bronchopneumonia.

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Personal experiences

35. The treatment and death of my brothers has had a profound impact upon me. I kept their conditions a secret from anyone outside the family. In recent years I have become more open with friends but still prefer not to discuss my family history in detail.
36. Prior to **B1** death, I was dating a man who became my first husband, **GRO-B: H**. When he proposed, I decided to marry him to show the family, and particularly my brothers, that I was happy. The wedding was arranged and a week before the wedding day, **B1** health deteriorated and he sadly passed away. I decided that the wedding would go ahead and **B1** funeral was held the following day. My marriage to **H** broke down the following year. I do not think **H** ever understood the impact that my brother's death had on me and he was not supportive at all after we were married.
37. After my divorce, I moved away from where my family lived for a fresh start, and to try and reinvent myself. I began working for a family as a Nanny in 1987. I recall going to work the day after **B3** death. I and tried to cope without my employer knowing what I had experienced. I felt that I could not tell them about my brothers for fear of losing my job, in case they would not let me care for their children anymore. Eventually the family found out that my brothers had died, but I initially told them the cause was cancer. The family were very supportive so I decided to tell them the actual cause of death. I was scared that they would accuse me of risking the cross-infection of their children, but instead they were incredibly caring and supportive.
38. Sometime in 1995 I did seek help from the GP for depression and anxiety. I was told that an appointment was not available for seven days and that if I needed to talk, I should contact a friend. I was then referred to Cruse Bereavement and saw a counsellor on a weekly basis, until she sadly passed away. At that stage I had left my job as a Nanny but the family allowed me to live in an annex to their house and later paid for me to see their private doctor who then referred me to a therapist for counselling. They were very kind to me

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for as long as I knew them. When **B3** was still alive they had offered to install air conditioning in my father's home to ease **B3** pain, but we felt that this was not their responsibility and so we declined their kind offer.

39. I was extremely vulnerable, underweight, had constant nausea and for some time I did not have a permanent home. I had a part time job as a receptionist because I did not feel strong enough to work full time.
40. I joined my local gym and soon afterwards I met someone who I began a relationship with. I fell pregnant but he left me before our daughter was born. During pregnancy my depression escalated. I could not cope on my own and began living with my sister, who for some time cared for my newborn daughter because I was unable to.
41. I was eventually prescribed anti-depressants which remarkably improved my symptoms, to the point where I stopped needing to attend counselling sessions. My eldest daughter's father tried to get full custody of her when she was four years old. This was a battle that took six years to resolve and did not help my mental health. During this time my second daughter was born.
42. My sister and I do not discuss our brothers and we do not have photographs of them on show. My children are not aware of the full extent of the pain and suffering we experienced through their illness and death, which is still raw today.
43. I have another brother, **GRO-B: B4** who is estranged from the family. **B4** does not have haemophilia but was diagnosed with epilepsy at 17 years of age. He went to university and later married and had two children. **B4** was a fantastic brother. I do not know the impact my other brothers' condition and deaths had on him.
44. When **B4** was 40, he had a stroke. At the time, I was experiencing severe depression and did not have the strength to support or help him, neither did my

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sister or father **B4** drifted from the family because he felt so unsupported. I regret our actions and feel incredibly guilty still, but at the time, further strain on my mental health would have caused irreparable damage **B4** now lives in a care home and I have not seen him for many years.

Section 5: Treatment/Care/Support

45. I am aware that my brothers were treated at St Mary's Hospital in Paddington, Royal Free Hospital in London, John Radcliffe Hospital in Oxford and then Nuffield Orthopaedic Centre in Oxford, where all three of my brothers sadly died.
46. It was rare for my brothers to visit the local GP, instead they would go to a specialist haemophilia clinic or directly to hospital. They continued to be prescribed Cryoprecipitate after it was known to be contaminated. Doctors had said that if the blood product was heated, the risk of contamination was eliminated, but the cost of the heat-treated blood product was expensive. I do not think my brothers were ever given the heat-treated product.
47. We were offered very little support or sympathy from the hospital staff at Churchill Hospital. As a family we felt ashamed, and looking back that was the wrong attitude to take but we were made to feel that way. I recall on one occasion visiting **B1** in hospital, not long after **B3** had died. I remember the staff moved **B3** body from the ward whilst we were visiting **B1** which I thought was very insensitive. They had put his body in a black body bag, and that image still haunts me to this day. When **B3** died we were handed his belongings and just left. We were offered no support or guidance. We just had to deal with it.
48. All three of my brothers were under the care of Dr Matthews, who was a good doctor but seemed to lack any empathy. They were then cared for by Dr Giogrande at John Radcliffe Hospital, who was caring, helpful and above all

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was open about treatment and prognosis. Their experience of other doctors was not pleasant.

49. My memory of the treatment offered is poor but I can recall **B1, 3** and **B2** all being prescribed morphine for pain management towards the end of their lives. I believe **B2, 3** and possibly **B1** as well were prescribed AZT for treatment of their HIV infection towards the end of their lives. I do think that treatment of their symptoms was given priority over treatment of the HIV infection or AIDS itself.
50. When **B3** and **B1** passed away we were not allowed to dress them, instead clothing had to be placed on top of a closed coffin and we were not allowed to see them. **GRO-B: B3P** arranged **B3** funeral, and so I cannot comment on whether she came across the same issues.
51. My husband is aware of my history and that all three of my brothers sadly died. He is incredibly supportive, as are my two children. My sister and I are becoming more open about discussing our brothers with our families and close friends but the heartbreak we suffered over the years will continue to affect us for the rest of our lives.
52. I continue to suffer from anxiety and take anti-depressants to control my depression. I do not think that I will be able to stop taking the medication for fear of having a nervous breakdown. This Inquiry has brought back painful memories and I do not want my health to deteriorate again. However, I want closure and to speak about my brothers without feeling ashamed.

Section 6: Financial Impact

53. My parents did not ask for and were not offered financial support whilst we were growing up. My father worked but had a limited income so we all lived in a small house and had very little money.

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54. Before he died, **B3** paid for my father's mortgage on a monthly basis, from his wages, because he was on benefits and was at risk of losing the house. When **B3** died, my sister's husband took over this responsibility, but it was agreed that when the house was sold, this money would be repaid. Once my father went into a nursing home, Social Services tried to ring fence the money to pay for my father's care. Eventually, my sister's husband was able to claim the money owed but it was a difficult and stressful process, taking many months to resolve.
55. **B3** worked so did not claim benefits. Both **B1** and **B2** received mobility allowance. I am not aware of any other benefits claimed.
56. I am aware that each of my brothers received £20,000 each from the Skipton Fund. As far as I am aware there were no issues with their applications or the funds being granted.

Section 7: Conclusion

57. My brothers' illness and deaths had a profound impact on me, that I continue to suffer today. I hope this Inquiry can get to the bottom of how this was allowed to happen.

Statement of Truth

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

Signed:

GRO-B

Dated:

29-02-2020