Witness Name:

GRO-B

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|         | Statement No: WITN 1508001   |
|         | Exhibits: 0  |
|         | Dated: 27 February 2019  |
|         |  |
|         |  |
|         | INFECTED BLOOD INQUIRY   |
|         |  |
|         |  |
|         | FIRST WRITTEN STATEMENT OF GRO-B   |
|         | <u> </u>   |
|         |  |
|         |  |
| 1, 0    | GRO-B will say as follows:-  |
| Section | on 1. Introduction   |
|         |  |
| 1.      | My name is GRO-B My date of birth is GRO-B I live with my partner at GRO-B   |
|         | my partiter at   |
|         | ,  |
| 2.      | This witness statement is prepared as the son of GRO-B: M who  |
|         | was infected with HIV by my late father, GRO-B: F My mother was born on GRO-B and died of AIDS on GRO-B She was aged GRO-B   |
|         | at the date of her death.  |
|         |  |
|         | processing and the second seco |
| 3.      | My father was born in GRO-B (his exact date of birth is unknown) and   |
|         | he died of AIDS on GRO-B 1993. He was aged at the date of his death.   |
|         |  |

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|    | 10             |       |  |      |
|----|----------------|-------|--|------|
| 4. | I have         | GRO-B | two are older than me and one who is younger GR    | lO-B |
|    |                |       | GRO-B  |      |
|    | GRO-B          |       |  |      |
| 5. | My eld<br>GRO- | 1     | made a separate statement for our father under GRO | -В   |

This witness statement has been prepared without the benefit of access to full medical records for my mother.

# Section 2. How Affected

- 7. In 1984, my father and mother had met and were living together in GRO-B

  GRO-B

  I believe I was conceived from this relationship before my father was HIV positive and was infected with Hepatitis C.
- 8. I was aged 6 when my father died and 9 when my mother died. I have some recollection of my father but my eldest GRO-B who is easy years older has been able to tell me more about him. Apart from the issues he had with his blood not clotting like a normal person, he was a fit and able man and he led a normal life.
- 9. However, due to his condition, he used to avoid getting bruised because this would usually lead to a bleed that had to be stopped by doctors at the hospital. I now know this is a genetic disorder called Hemophilia and is passed from one generation to the next. I understand that Hemophilia is inherent on my father's side of the family.
- 10.1 believe Factor VIII (FVIII) products came onto the market to treat hemophiliacs, in the early 1970s, when my father was a teenager. I also

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believe that whenever my father had spontaneous bleeds the doctors treated him with these products.

11. I believe that the FVIII products were not safe to use because these contained blood that was contaminated. I believe the doctors failed to inform my father he had been infected with HIV and carried the risk of passing the virus onto others. I believe that if my father had been advised of the dangers of infecting others and about the routes of transmission, he would have ensured that he did not infect my mother. My father would not have endangered my mother's life.

12. My father's hemophilia was treated locally by doctors in a hospital in north west London GRO-B I do not know the names of the doctors who treated him. I do know that they continued to treat him with Factor VIII until the last year of his life.

13. I do know if my mother was told by doctors she had been tested positive for HIV which was transmitted by my father. There are many unanswered questions and I have attempted to obtain medical records with a view to ascertaining why both my parents were allowed to die in the way they did. I have managed to obtain some of my mother's records, but not all.

#### My Mother's medical records

14. There is a number of letters from the NHS to a consultant at Northwick Hospital London that confirms my mother was infected with HIV in December 1989. There are other letters and records that are vague and not legible so I do not know exactly when she was infected. I do know that these records that I have been sent are incomplete.

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| entries regarding the infection and neither are there any entries that refer to my father with whom she was living at the time.   |
|---|
| 16. Soon after her death, I was left traumatised. There was no one to take care of me so I was sent to live with my uncle who lived in GRO-B about 100 miles away before moving to my grandmothers and then with another relative. In the space of a few years, my life was turned upside down. I was both confused and angry so much so, that when I was living with my uncle, I found myself looking for letters relating to my mother. I came across one such letter which stated she was HIV positive and when I found it, I did not know what to do with it. I was very young and was unable to speak to anyone about it because I was struggling to understand and accept what I had read. I stayed with my uncle for 2 years after my mother had died. |
| 17. My uncle took care of me from the ages of 9 to 11 and then moved to live with my grandmother from 11 to 14. When she died, I went to live with another uncle from 14 to 17. I lived in GRO-B throughout these years and unfortunately lost contact with my eldest sister.   |
| 18. I was unable to find any further letters until I was 17 years of age. That is when I was contacted by the Macfarlane Trust, who told me that I was entitled to a sum GRO-B which it had already paid to the trustees of my mother's estate.   |
| Section 3. Other Infections   |
| 19. I believe my mother was infected by HIV and Hepatitis C only. If she had any  |

other infections, I do not know about it.

#### Section 4. Consent

- 20. I do not know what the hospitals told my father about any treatment it was giving to him for his haemophilia. My father would have accepted the hospitals needed to stop the spontaneous bleeds. I do know from my own research that FVIII products were being used to treat his condition from his teenage years. I believe the hospitals failed to tell him of the source of the blood that was being used and failed to give him adequate or full information about the risks associated with receiving Factor VIII. If he had been advised properly, he would not have consented to it.
- 21.I believe that the hospitals failed to give my mother any or adequate information about my father's HIV. Due to its failure, my father infected my mother with it as he was unaware of the virus at the time of transferring. If the hospitals had advised her properly, she would still be here today.

## Section 5. Impact

# Impact of the infection on my mother

- 22. My mother worked in the Accounts Department in London. I do not know what, if anything, the doctors advised her about being infected with HIV. I always remember her smiling and being happy perhaps trying to conceal from me that she too was going to die.
- 23. Around 1991, my mother stopped working due to mental and physical illness. By now, I believe the effect of the HIV was beginning to have an effect on the functioning of her organs. She was always quite slim but I could tell she was losing a lot of weight and her complexion had changed.
- 24. In the last year of her life, my step-father arranged for her to sleep in the lounge downstairs because she was no longer able to walk up and down the stairs. I could tell my mother was very ill but I did not know the reason why.

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My mother spent the last months of her life in the Royal Free Hospital where she died.

- 25.1 last saw her when I was at home and she left to go into hospital. Her birthday was coming up so I bought her a gift the day before she passed away. I wanted to give her the present in the evening. My grandmother would not let me give it to her because of her condition and told me that she would take it to her. My mother died the next day. She was on life sustaining equipment and I think my grandmother did not want me to see her suffering.
- 26. The last time I saw my mother was in her open casket at her funeral. I had not seen her for a few months before that. She had her make-up done and I believe that sight was not the true reflection of her health leading up to her death.
- 27. The HIV infection completely destroyed her social and private life. She did not go out socially from date of being diagnosed. Before then, she was very socially active with her family and friends.

#### Impact on me

- 28. The loss of my parents had a devastating effect on me. I was bubbly and enthusiastic but after they died, I became quiet and reserved and my mind seemed to be pre-occupied trying to establish what was going on and why. For this reason, I did not do well at school. When, I first moved to GRO-B , I did not know how to channel my emotions. I used to storm out of the classrooms in a rage and this was all due my anger of losing my parents.
- 29. Upon completing my secondary education, I went to college in my 20s. I completed a B-Tec Business Course but I had to re-sit exams which I consider

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I would not have had to do if my parents had not died. I did find it really difficult to concentrate during this period.

30. The passing of my mother destroyed my life. The person I am today is not the person I would have been if this tragedy had this not happened. I have had to carry a massive burden since my childhood broke down. I shifted from home to home and did my best to manage despite being physically, and mentally exhausted.

# Impact on rest of the family

- 31. My sister who is the youngest was 2 years old when our mother died. At some stage afterwards, as a teenager she used to cut herself in her mid-teens. She would often be in tears breaking down, asking why her mother left her.
- 32. My grandfather was deeply affected by my mother's passing and still breaks down to this day. I last saw him in October. It is very hard for me to see him like that.
- 33. My mother's siblings took advantage of my mother's estate for their financial gain. They extracted a large amount of cash from the estate. They extracted £300 a week, which is GRO-B a month for looking after me. I was only a 9 year old child and they took full advantage of my vulnerable state.

## Stigma of HIV

34. Due to the stigma associated with HIV, I avoid talking about the cause of my mother's death. Only my direct family knows about it and did my best to conceal it from others. However, my two previous partners carried out their own research and found out about the situation and this caused a break-up in our relationship. They were afraid that I could have contracted HIV and be directly infected.

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| 35. When I moved to GRO-B I had tests to see whether I contracted the HIV virus, but thankfully these came back negative. If people ask about the cause of my mother's death, I tell them that my mother died of kidney infection because of the stigma associated with HIV.        |
|---|
| 36. My mother's cousin was the executor of her estate which was worth  GRO-B at the time of her passing. My GRO-B and I only received  GRO-B by the time the distribution came to an end.   |
| Section 6. Treatment/Care/Support   |
| 37.1 do not know if my mother faced any difficulties or obstacles obtaining treatment.  |
| 38.1 was not offered any counselling in secondary school. I was seen by a<br>counsellor but this was in relation to my behaviour in class and not because<br>my parents had died.   |
| Section 7. Financial Assistance   |
| 39. I do not know what financial assistance my mother received from the local government or Support Aid groups.   |
| 40. I was informed by the Macfarlane Trust that I was owed money when I was 16 years old. When I was contacted by the Macfarlane Trust, I was in hospital. I had an operation which went wrong and I was paralysed for approximately one year. I was told I would never walk again. |
| 41.I was told by the Macfarlane Trust that I was due to receive GRO-B when I was 16 years old but because I was a minor, it was paid to the trustee of the estate who was my uncle. It was my uncle who completed various application   |

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| forms for trust funds on my behalf without my consent and obtained the funds |
|--|
| without my knowledge. I was not given the full amount which I was owed. He   |
| only gave me GRO-B after I had confronted him about the funds. I believe     |
| that my uncle was rightfully entitled to GRO-B of the GRO-B so he            |
| should have given me GRO-B   |

- 42. The Macfarlane Trust gave him the money in good faith. I believe that the situation could have been handled better by the Macfarlane Trust, by waiting for me to reach 18 before they transfer the funds directly to me.
- 43. I was later made aware of the Skipton fund through the Macfarlane trust. My application to the Skipton fund was rejected due to lack of evidence. Due to stress, I lost all enthusiasm and lost control of my financial affairs. I do feel the Skipton Fund was wrong to reject my application and wish to lodge an appeal against their decision.

| 44. | In 2   | 013 or 2014, my step mother     | received an ex-gracia payment of GRO-       | В   |
|-----|--------|---------------------------------|---|-----|
|     | and    | GRO-B                           | which has not been distributed. It was pa   | iid |
|     | to th  | ne executor of my father's esta | te. It should have been distributed between | ∍n  |
|     | all ti | he three of his children We a   | re currently going though the small clain   | ns  |
|     | cour   | rt in order to claim some of th | e money. This situation should never ha     | ve  |
|     | arise  | en.                             |   |     |

## Section 8. Other Issues

45. My father was primarily infected by receiving blood products. My mother was infected subsequently by him. This should not have occurred. I lost both father and mother as a result of this. Prior to my father's infection, my mother was perfectly healthy. The NHS are to blame for the loss of both of my parents. I will spend the rest of my life wondering what my life would have been like if

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they were still with me and their grandchildren.

# Anonymity, disclosure and redaction

- 46. I would like to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.
- 47. I do not wish to be called to give oral evidence.

#### Statement of Truth

| I believe that | the facts stat | ted in this witness statement are true. |  |
|----------------|----------------|---|--|
| Signed         | GRO-B          |   |  |
| GRO-B          |                |   |  |
|                |                |   |  |

Dated 27 February 2019