Witness Name:

Statement No: WITN1767001

**GRO-B** 

Exhibits: 0

Dated: February 2020 INFECTED BLOOD INQUIRY FIRST WRITTEN STATEMENT OF GRO-B will say as follows:-**GRO-B** Section 1. Introduction **GRO-B** and I was born on **GRO-B** 1. My name is 1 live GRO-B I have one son who has severe Haemophilia. has also provided a witness statement to the 2. My mum, **GRO-B** Inquiry under witness number GRO-B

 This witness statement has been prepared without the benefit of access to my late dad's full medical records.

who was infected with HIV via contaminated blood products. He was born on

**GRO-B** 

3. I make this statement as an affected daughter of my late dad,

and passed away on

GRO-B

35.

at the age of only

## Section 2. How Affected

- 5. My dad had severe Haemophilia A; suffered with joint bleeds and was affected by his condition throughout his life.
- 6. My dad was mainly treated at the Royal Liverpool Hospital in Liverpool. His treating physicians included Dr Carty, Professor Robert Owen, Mr Shatwell, Mr Alistair Turner, Dr Van Dettel, Dr J Kelly Dr Bartzokas, Dr Robinson, Dr Mackie, Dr Galloway, Professor Duffy and Dr McVerry.
- 7. My dad self-administered Factor VIII concentrates at home from around 1983. He also received numerous blood transfusions in 1984-1985 following surgery and was also given up to eight doses of Factor VIII concentrates each day.
- 8. My dad was not given any information or advice regarding the risk of infection from Factor VIII concentrates.
- 9. I do not know when my dad was infected with HIV but he first displayed clear indications of a suppressed immune system and a rapid decline in health from 1984 onwards. I defer to my mum's witness statement for more information in relation to my father's declining health and diagnosis.

#### Section 3. Other Infections

10. As far as I am aware the only other infection which my dad was exposed to was Hepatitis C.

## Section 4. Consent

11. My dad was tested for HIV without his knowledge and therefore without his consent.

## Section 5. Impact

- 12. I was aged only 9 when I lost my dad through contaminated blood products.
- 13. During my childhood I spent much of my time visiting my dad at the Royal Liverpool Hospital. Hospital staff made us wear gloves and an apron in the latter stages when we went in to see him. I didn't understand why we had to wear them although now I suspect it was because they knew he had HIV. I would remember my dad asking me to take them off.
- 14. However, when his health started to deteriorate as a result of the HIV attacking his immune system, my mum decided that it was best that I didn't see dad in the condition he was in. Mum considered my young age and how I may not understand what was happening to dad and she decided to send me to live with my auntie.
- 15. My dad passed away, aged only 35, on GRO-B and I returned to a broken family. I remember distinctly that an article in the local newspaper in GRO-B where we lived came out, revealing that my dad had died of HIV. I got comments in the playground about not going near me because of my dad and his illness.
- 16. We ended up moving north to **GRO-B** so I lost not only my dad, but my home and had to cope with a new school and making new school friends. I struggled to understand this as a nine year old and I grew to resent my mum. I was too young to understand why we had to move and I did not know who to blame except her. Looking back I can see the difficult choices she had to make, but when I was a child, I could not. There was no counselling following dad's death and no explanation as to why he had died. There was no support for either myself or my sister. My world had been shattered and I could only process that through my mother, for good or ill.

- 17. For her part, my mum then had to cope with not only the loss of my dad (her husband) but had to now support two children alone at the age of only 32. It reached the point that at the age of 15 I ended up spending some time living with my dad's parents on and off until I was 17 due to the troubles between us. While things are much better now, the impact of my dad's death upon my childhood and our family relationship is something I still struggle with.
- 18. On the other hand, my sister and I grew very close during our teenage years and both of us left home early. We lived together in a flat when we moved out of home at the age of 17. She is a CAFCASS officer and I remark now how we both went into careers that involve supporting children, which perhaps reflects what we lacked.
- 19. As a young girl I always wanted to have and do things that my friends were doing, not understanding that they had two parents to support them financially compared to my one. My mum struggled and it is only now, at the age of 43, I myself can understand how hard it was. My marriage broke down when my son was 4 so I am also a single parent and have a fourteen year old son with severe Haemophilia.
- 20. Mum struggled to support me financially through both of my degrees, despite the fact that she tried hard and worked away and for long hours. I ended up having to fall back on student loans.
- 21. I did achieve both mine and my dad's goal which was for me to become an GRO-B

  GRO-B

  However, this career had to be placed on hold because of my son's condition and I have had to often act as my son's full time carer. I was unable to return to permanent roles due to having to arrange my work around my son, and so I have had to work as a temporary supply teacher. My earnings have therefore been lower than I had hoped. With dad being around to support me, and more importantly my son, I think I would have been able to provide for us better. Dad would also have been much better able to talk to and understand what my son is going through and I wish he was here to do that. My son is now aged 14 and I have to inject him three times per week with Factor VIII. I have to be available to treat him as and when required.

- 22. It has been really hard trusting the NHS and sometimes I felt uneasy injecting my son with Factor VIII after losing my dad through contaminated blood. For example, I was asked by Alder Hey Children's Hospital in Liverpool to allow a shift of manufacturer for my son's treatment from the pharmaceutical company Bayer to one called Novo Nordisk. Due to what had happened to my dad I was reluctant to allow this change, it was simply hard to trust a new product. It was only when the change was mandatory due to budgeting reasons about a year ago that my son's treatment ended up being changed. This year, a further new treatment is being proposed that will allow my son's blood to clot longer and again I feel the same gut wrenching feeling of mistrust and question whether he should change over, despite knowing it will be positive for him.
- 23. Dad's death even today evokes feelings of anger and sorrow in me, knowing that he died through pure negligence on the part of the Government. I try not to research the contaminated blood issue as I do not want to be consumed by anger and I also have to support and reassure my son.

## Section 6. Treatment/care/support

24.1 refer to my mum's statement in this regard. I have never been offered any counselling or psychological assistance in consequence of my dad's infection and subsequent passing.

#### Section 7. Financial Assistance

- 25. I refer to my mum's statement in this regard.
- 26.1 have never received any financial or practical assistance from either the Macfarlane Trust or the EIBSS.

## Section 8. Other Issues

27. My family have suffered so much financial and emotional stress and I fully support the victims' plight to gain answers and deserved compensation.

# **Anonymity**

28.I want to apply for anonymity and I do not wish to give oral evidence to the Inquiry.

## Statement of Truth

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

Signed	GRO-B	
Dated	01/04/20.	j