Witness Name: GRO-B

Statement No:WITN2564001

| Dated: 12 <sup>th</sup> March 2019  |
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| INFECTED BLOOD INQUIRY  |
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| FIRST WRITTEN STATEMENT OF GRO-B  |
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| I provide this statement in response to a request under Rule 9 of the Inquiry |
| Rules 2006 dated 12 December 2018. I adopt the paragraph numbering in the     |
| Rule 9 request for ease of reference.   |
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| I, GRO-B will say as follows:-  |
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| 1. Introduction   |
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| 1. My name is GRO-B . My date of birth is GRO-B and my                        |
| address is known to the Inquiry.  |
| 2. How infected   |
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| 1. My brother, GRO-B: B was born with severe Haemophilia A. Due to            |
| his condition, when my brother suffered a bleeding episode he was             |
| required to attend the GRO-B  |
| GRO-B It was during treatment for a bleed at the GRO-B that my brother        |
|   |

was given infected blood products which resulted in him being infected with the HIV and hepatitis C virus.

- The nature of my brother's haemophilia condition and the blood products he received will be provided in his witness statement to the Inquiry. My brother's witness statement to the Inquiry will also confirm when he was informed of this condition.
- I am unsure when my brother was told about being infected by HIV and hepatitis C as my parents did not tell me for some years later. My brother's witness statement to the Inquiry will confirm when he was informed.
- Due to the bad batch of blood my brother received be became infected with HIV and hepatitis C.
- 5. I remember when I was told about my brother's condition. I was taken into the 'posh lounge' where my father stood and told me that my brother had been infected with HIV. I had a lot of questions but my parents were unable to answer them. A few years later I was made aware that my brother had also become infected by hepatitis C. There was not a lot of information about HIV at this time. We just believed my brother's days were numbered. When my parents told me about my brother, I remember feeling numb and did not really believe it was happening. Also, it became something we didn't talk about due to it being so upsetting for my parents.
- 6. As stated above, I am unsure when my parents and my brother found out about his condition and so I am unable to confirm what information was provided at the time. I also do not have any views about how the information was provided to my family as I was not a part of this. I do remember being told that I needed to be careful around my brother's blood.

#### 3. Other Infections

I am not aware of my brother suffering from any other infections.

### 4. Consent

1. My brother was treated for a bleed with my parents consent at the GRO-B when he was wears old. I am unsure as to what, if any, information they were given at that time.

#### 5. Impact

- 1. Prior to being told about my brother's condition, I would see my parents treat my brother differently. For example, he would always have the latest trainers and would go on holiday without me. At Christmas time he always got spoiled. At the time I did not understand why, and this impacted me growing up. Now I understand, this was because my parents believed that they had very little time left with my brother.
- 2. My brother's condition was something I had to deal with on a daily basis. I would feel upset and guilty and still do. It is like my brother has a constant death sentence and I was fearful that I could lose my brother at any time. I'm sure this strain contributed to my parents' relationship breaking down.
- 3. I was also left with the feeling that I did not want children. As I am a carrier for haemophilia, there is a possibility that my children will also suffer from haemophilia, requiring treatment for episodes of bleeding. I was in fear that my brother's situation could repeat itself with my children. Although I now have GRO-B children, I did not have my GRO-B child until gross years after marrying my husband due to my fears. It also impacts me when I am out and about and hear someone make a joke about HIV/AIDS.

- I do not know of the psychological impact this had on my brother as we do not speak about the situation. I am aware that my brother now receives counselling.
- 8. I remember the physical impacts on my brother. When he was younger he was always ill and looked frail. He would have times of sickness and weakness, not always being able to make it to the bathroom. My brother also required a lot of medication and was admitted to hospital a lot due to the side effects of his tablets. My brother's medication was changed regularly as the health professionals worked out what medication and treatments worked for him and what did not. I believe that my brother received new medications and treatments as they became available on the NHS. My brother has become immune to previous medication and he has been told that should he become immune to his current medication, no other tablets are currently available. I am not aware of any difficulties my brother has faced in regard to assessing treatment. My brother will provide this information in his witness statement to the Inquiry
- 9. I feel that my brother's condition is like a constant death sentence. My brother did not have a normal teenage life. He had some periods of normality but longer periods when he was housebound and poorly. My brother's condition impacted his school life too. He was unable to attend a mainstream school due to the amount of school he had already missed. Instead, my brother went to a special education school. This made things worse for my brother as he did not generally need special education; he just missed a lot of school. The qualifications my brother received were therefore impacted. However, my brother has done amazingly well despite this. He attended night school and gained qualifications and a job while carrying his burden and treatments.
- 10. When my brother began a relationship I was pleased, however I was also concerned at all the things his girlfriend would go through living

with a person with hepatitis C. Thankfully, my brother has his own children now, but I constantly worry what will happen to his children and GRO-B should the worst happen to my brother.

11. My brother's career has been impacted by his condition due to amount of time he takes off due to being ill.

### 6. Treatment/Care/Support

1. I have not received counselling or psychological support but my brother is currently receiving counselling. I am unable to comment on whether this support is adequate as me and my brother do not talk about his counselling. We try to normalise all situations and conversations for him. This information should be within my brother's witness statement.

## 7. Financial Assistance

I am unable to comment on the financial assistance received. This
information should be within my brother's witness statement. I do
however believe that my brother should receive financial assistance. I
would like my brother to not have to worry about his family's financial
circumstances should the worse happen to him.

#### 8. Other Issues

1. One of my GRO-B also suffers with Haemophilia A. Due to my brother's experience; I want GRO-B to receive synthetic treatment for this condition. When my family lived in GRO-B GRO-B was offered this treatment as a trial. However, once the treatment had been cleared for use, GRO-B was no longer allowed this treatment. We therefore had to move back to GRO-B in order for GRO-B to have synthetic treatments in order to avoid the risk of GRO-B becoming infected. I believe that considering what we had gone through with my

| brother and contin | ue to go through, | the refusal  | of the        | GRO-B  |
|--------------------|-------------------|--------------|---------------|--------|
| GRO-B              | to provide synthe | tic treatmer | ıt is unforgi | vable. |

# Statement of Truth

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

Signed: GRO-B

Dated: 12.3.19