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Witness Name: **GRO-B**

Witness Number: WITN2508001

Dated: 13th January 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, **GRO-B** will say as follows:-

1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B**
GRO-B and my address is known to the Inquiry.
2. I am married with **GRO-B** adult children.
3. I am the brother of **GRO-B** who has also made a Witness Statement to the Inquiry (**GRO-B**). My sister's statement will refer to medical records and contain any relevant exhibits.

2.How Affected

1. I make this statement in respect of my late brother **GRO-B: B** who passed away in **GRO-B** having received infected Factor VIII blood products.
2. **B** was employed by **GRO-B**
3. It was a coincidence that our grandfather, **B** and one of my first cousins were all diagnosed with haemophilia during 1966. **B** was aged five at the time of his diagnosis. Our grandfather who had worked as a **GRO-B** lived until he was **GRO-B** years old. He didn't require treatment at the hospital until his late **GRO-B**
4. My sister **GRO-B: S** (or **S** as she is known), **B** and I were close in age and we shared a very happy childhood. We had an active family life which encouraged **B** to be very sporty and become involved in a number of activities such as swimming, tennis, water skiing, surfing and cycling. **B** did not suffer serious problems with bleeding episodes and required treatment very infrequently.
5. **B** was diagnosed from childhood with 0% Factor VIII. His lifelong experience was of mild haemophilia. I understand that this is a rare but well understood clinical observation. Due to the mild nature of **B**'s haemophilia he would only go to hospital for treatment two to three times a year.
6. **B** received the majority of his treatment at the **GRO-B** **GRO-B** in **GRO-B**. He was also treated occasionally at **GRO-B** in **GRO-B** when a small Haemophilia Unit was set up there in the **GRO-B**s.
7. I understand **B** was initially treated with Cryoprecipitate up until **GRO-B** and then changed to Factor VIII. My sister and I are hopeful that

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this Inquiry will shed light on any policies that were in place at this time with regard to patient criteria for receiving Factor VIII products and the risks of contamination as understood by clinicians including the risk of hepatitis viral infections and infection with HIV.

8. [B] did not receive any advice or information on the risk before receiving blood products.
9. In 1985 our mother received a telephone call from [GRO-B]. They explained they wanted to speak to [B] urgently. He was however studying at [GRO-B] at the time of the call so our mother contacted Professor [GRO-B] at the [B].
10. At first Professor [GRO-B] explained that he had no idea as to why [B] would have been contacted by [GRO-B] but then after some persistence from my mother, he found a letter on his desk and informed my mother that [B] had become infected with HIV.
11. Professor [GRO-B] told our mother that she should not tell [B] of the telephone call and that he would see [B] when he next attended the hospital. He must have known that he would not see [B] for quite a while as he rarely needed to attend the Haemophilia Centre.
12. In November 1985 Professor [GRO-B] wrote to [B] requesting that he attend a meeting at the [GRO-B]. It was at this meeting that he learnt he had become infected with HIV. [B] was also advised to keep the information "strictly confidential" even from his immediate family.
13. [B]'s medical records show that the haemophilia clinicians knew of his HIV status much earlier to [B] being informed. These records are exhibited in my sister [S]'s witness statement to the Inquiry.

3. Other infections

1. I know that [B] was infected with HIV and hepatitis C but I am not aware of any other infections.

4.Consent

1. I believe [B] was treated with Factor VIII with his consent but he was not provided with any information in relation to any risk associated with blood clotting products and neither were the rest of the family.
2. [B] was treated with Cryoprecipitate until [GRO-B] when his treatment changed to Factor VIII. The introduction of Factor VIII products at this time would have been presented as a more convenient treatment for patients.
3. More recently, my sister and I have become aware of evidence that, even as Factor VIII was being introduced and widely distributed, the clinicians involved were concerned over the safety of these products with regard to contamination with hepatitis viruses. My sister's statement will explain this evidence in more detail.
4. I believe that as [B] was a mild sufferer and had received a comparatively low exposure to blood products, he fitted the required patient profile for hepatitis infectivity studies. I would like to know whether my brother was actually used in this way.

5.Impact

1. I find it difficult to complete this section of my statement. However, this doesn't mean I haven't been impacted by my brother's infection. In fact, it is quite the opposite.

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2. I find it very difficult to talk about the emotional impact of [B] receiving contaminated blood and for this reason, my sister has covered this section for the both of us in her statement to the Inquiry.
3. It was in [GRO-B] that [B] was first tested and made aware of his hepatitis C infection but we do not know for how long he had been infected with hepatitis C before he was told.
4. Due to the huge stigma at the time, [B]'s infection was kept secret by close family members. None of us felt we could confide in anyone outside of the family. I know this put a lot of emotional and psychological strain on [B]. It is sad that he didn't get to experience the companionship and comfort from a longstanding relationship.
5. I know that [B] was particularly unnerved by anyone at work finding out about his infected status as he worked within small semi-rural close-knit communities. He would worry that the hospital may call him at work and that should his employer found out about his infection, his employment would be terminated. [B] lost his self confidence and felt trapped.
6. Towards the end of [B]'s life he lost a great deal of weight; suffered skin rashes, jaundice and extreme fatigue. He didn't want anyone to see the condition he was in and so was very reluctant to receive visitors.
7. In June [GRO-B] [B] realised that he could no longer cope on his own and so moved back to our parents' home. Our parents took care of him until he was hospitalised. He died one week after being admitted to hospital on the [GRO-B] aged [GRO-B]. It was a huge shock to us all.
8. We miss [B] terribly but especially miss him at large family gatherings; he was such a big personality.

9. Our parents quietly and tirelessly campaigned for [B] to obtain some financial independence as his future was so unpredictable. They assisted [B] with litigation in the late 1980's. My sister's statement provides the specific details of this litigation.
10. Our parents' retirement was blighted by the fear that someone would find out about [B]'s condition. As a consequence, they tended to shy away from social events. This was due to the fear of what lay in wait for [B] as well as the stigma surrounding HIV. Our parents suffered significant distress and torment whilst nursing [B] in his final months. They never got over it.

6.Treatment/Care Support

1. No treatment or support was provided to [B] after his diagnosis. He was just left to cope with this huge bombshell on his own. It was fortunate that he had a loving and supportive family around him.
2. In the final year of his illness [B] received very good care, support and kindness from his doctors and nursing staff at the [GRO-B]
3. No counselling or psychological support was offered or provided to the family after [B]'s death.

7.Financial Assistance

1. My sister's witness statement to the Inquiry provides information in relation to financial assistance.

8.Other Issues

1. My sister's witness statement to the Inquiry will cover further issues in detail that we feel need to be brought to the attention of the inquiry.

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Statement of Truth

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

Signed....

GRO-B

Dated.....

13/1/20