

Witness Name: GRO-B

Statement No. WITN2441001

Exhibits: WITN2441002-WITN2441003

Dated: 28<sup>th</sup> February 2019

## 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<sup>th</sup> 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- I live at GRO-B

2. I am writing this statement to record my experience of growing up with a brother who had Haemophilia A and of my experience of being a Haemophilia carrier. I was confirmed as a carrier in 1980, after which I went on to give birth to two Haemophiliac sons in GRO-B and GRO-B

### 2. How Affected

1. My brother, [GRO-B: B] was born on [GRO-B] and had Haemophilia A. He trained and became a qualified [GRO-B]
2. [B] died in 1990, aged [GRO-B] of AIDS related illness following contracting the HIV via contaminated Factor VIII sometime in the 1970s or early 1980s. His widow and children are Core Participants and will provide details, in their own statements, of the nature of [B] medical history, treatment and the circumstances leading to his death in [GRO-B] 1990.
3. During our childhood we lived in [GRO-B] When [B] suffered an accident or bleed, he would be driven by ambulance, with a police side rider, to the University Hospital of Wales in Cardiff, a journey of some [GRO-B] A letter [GRO-B] in my eldest sons' medical notes from Dr P W Collins, Consultant Haematologist University Hospital of Wales to Dr Bolton-Maggs, Consultant Paediatric Haematologist Alder Hey Children's Hospital, states that my brother [B] was the first patient with Haemophilia to be treated by Consultant Haematologist Dr Arthur Bloom in Cardiff.
4. Once he qualified as [GRO-B] [B] worked and lived in Cardiff. Following his marriage and the birth of his two children, [B] and his family settled in the [GRO-B] from the early 1970s until his death in 1990. During this time [B] remained in the care of Bangor Haematology Department under the care of Consultant Haematologist Dr Tom Korn who I first contacted in 1980 regarding finding out whether I was a carrier.
5. It is my view that [B] may have already been infected during the period I was consulting with Royal Liverpool and Ysbyty Glan Clwyd Hospitals for advice as to whether I was a carrier. I had met my future husband and was planning to marry in [GRO-B] In 1980, Dr Korn referred me to Consultant Haematologist Dr B A McVerry at the regional Haemophilia Centre based in the Royal Liverpool Hospital. I

attended about three or four appointments over two years. I have kept my letters from Dr McVerry who confirmed that, though borderline, there was a strong possibility that I was a carrier and I was offered an opportunity to consider the new developments in amniocentesis "which allow, with a certain degree of certainty, to state whether a baby may have Haemophilia or not."

6. During the period between 1980 and 1982 I was carefully considering:
- a) obtaining advice about whether I was a carrier. b) whether I should have the new amniocentesis procedure, which had a high risk of miscarriage at that time and c) whether I should have children at all.

7. I do not recall if my brother was aware of the emerging serious nature of the concerns of viral contamination of Factor VIII in the global haemophiliac community during this period when I was talking to him about the decisions I was making. Indeed, he may even have already been unknowingly infected when we were talking about whether I should have children. I was certainly not made aware of the concerns of viral contamination that are now available and well documented in the Department of Health 2006 publication "A Chronology from 1973 to 1991 – Self Sufficiency in Blood". I made careful considerations with my husband about having children. An important influence was my experience of growing up with an active brother with mild Haemophilia A. He survived many childhood accidents and injuries having many periods of bed rest, as this was in the years before the positive emergence of Factor VIII. In his second year of GRO-B GRO-B in 1966, B had a serious GRO-B GRO-B and sadly had to have his GRO-B.

The operation was carried out at the Cardiff Royal Infirmary before Factor VIII was available as treatment. I was twelve years old and remember how it was the most worrying time with my parents and older sister being away from home in Cardiff with him for long periods.

8. Following the **GRO-B** **B** recovered, and was able to move forward and experience an improved quality of life experience that the new Factor VIII treatment offered Haemophiliacs. It meant treating a suspected bleed at an early stage and being able to live a more mobile and flexible lifestyle with fewer chronic bleeds. The introduction of Factor VIII made such a positive difference to **B**'s personal health and family life.

9. Regarding the dates or period of time my brother **B** was given contaminated treatment, I do not know the dates, and I guess if he did know, it was difficult to discuss his situation with me as he was dealing with the impact on him, and his immediate family at the time.

10. In the early 1980s the continuing development of Factor VIII as a new treatment was a big factor in helping my husband and I decide that if we did go on to have a son with Haemophilia, we would surely have a more positive experience than that of my brother growing up without Factor VIII.

11. With the benefit of hindsight, I do now wonder whether I could have been given more information about the emerging risks of viral contamination in 1980 to 1984. I became pregnant in **GRO-B** nearing the end of my pregnancy I remember sitting in my GP surgery reading a newspaper article about news that a virus was affecting Haemophiliacs in America. I remember feeling alarmed. In writing this statement about events that happened nearly forty years ago, I have thought about the fact that actually I could not have easily found out any more information myself as we did not have access to the internet, access to emails, mobile phones or 24 hour news channels, indeed you had to "catch" the news at 6 pm or 9pm. It was only by chance I read the newspaper article. I went on and had my son in **GRO-B** In August of that year he was diagnosed with moderate Haemophilia A. My medical case notes include a letter exhibit WITN2441002 dated **GRO-B** from my son's Paediatrician to my GP in which I

reportedly ask him "whether I should be worried about the possibility of AIDS occurring through the prescription of Factor VIII?" the letter says that I was advised that "it was really rather unlikely at present". I must have felt reassured, as I went on and had my second son in [GRO-B] [GRO-B] He was diagnosed with Haemophilia A in October 1985. It was following his birth in [GRO-B] that my brother broke the devastating news to us that he had in fact been infected with the HIV virus. What followed was an incredibly difficult and sad few years until his death in 1990. All the hopes of a positive experience if my husband and I were to have children with Haemophilia changed overnight and the worries started about whether they would require Factor VIII and whether it would be safe from contamination. In addition, there was the well documented and extremely alarming media coverage using words such as 'a plague' etc along with press reports of parents refusing to send their children to school when a child had been identified as a HIV positive Haemophiliac.

12. [B] informed me that he was HIV positive following the birth of my second son in [GRO-B] I do not know when he was informed. It was the advice of the medical profession to keep the details private at that time. It was also a period of negative press coverage for all victims of the virus with much fear and prejudice being shown to people in the community. As new parents of two little boys with Haemophilia, it was an extremely worrying and anxious time.

13. A letter exhibited at WITN2441003 dated [GRO-B] from our Paediatrician to the Clinical Medical Officer gives a clear idea of the tensions and worries we had as parents during this time: *"These two children have classic Haemophilia. It is going to be important from Mrs [GRO-B] point of view particularly that all information about this, especially the question of whether they have received Factor VIII concentrate, should be held very confidentially indeed, given the unreasonable and unfair publicity afforded to other haemophiliacs since the risk of A.I.D.S has become more widely known amongst the*

*general public. If correspondence is held about these children, I am sure it be carefully annotated and kept well clear from the appropriate schools except when it is important that the case folder is taken there."*

14. However, the most devastating thing at the time was the fear that the boys were going to lose a lovely uncle and I was going to lose my much-adored big brother who, in my mind, had always meant be there to support the boys, understand what it was like to grow up with Haemophilia and be their mentor. My brother was such a good role model who enjoyed [GRO-B] [GRO-B] and was always such a full-on character to be around. With hindsight, I do believe it must have been very difficult, however close we were, for my brother to tell me about his HIV status during the period I was thinking about and having children of my own.

15. I think my brother would have been terribly distressed and angry when immersed in coming to terms with the outcomes for both him and his young family of being infected with the HIV virus. That is why, I now wonder if any of the medical personnel, knowing the families in such a small region like North Wales, involved with both his care and involved in my enquires in the early 1980s, could have possibly advised me in a different way. Perhaps giving me more information about the emerging risks regarding viral contamination at that period when I was wondering whether or not to have children?

16. My brother provided me with information regarding minimising the risk of infection. We, as a family, were then just careful with personal hygiene at a time where media images of nurses in 'space suits' caring for patients were seen on TV along with adverts with tombstones and dark images. Our families remained close and my boys loved playing with their uncle and would play with their toys under his bed in his hospital room. They were aged just [GRO-B] and [GRO-B] years when [B] died.

17. I was not involved in [B]'s medical care and cannot answer questions regarding any information he was given or not given.

### 3. Other Infections

1. I do not have details regarding whether my brother [B] had any other infections other than HIV. Regarding my sons, I would like to emphasise that I feel my children were just 'lucky' that they did not receive Factor VIII treatment until the eldest was aged [GRO-B] in 1991 and the youngest was aged [GRO-B] in 1994. The care from our local hospital, Ysbyty Glan Clwyd, was very supportive and the outreach support from Alder Hey was excellent providing them with the skills to self-administer Factor VIII in the 1990s in order to on to lead full and active lives. However, in 2004, when my sons were aged [GRO-B] and [GRO-B] years old and living independently, they were very shocked to receive a letter through the post one day, informing them that they had been identified as 'at risk' of vCJD through clotting factors derived from UK sourced plasma. They were upset and worried at the time and both feel they should have been invited to attend their surgery or Haemophilia Centre to receive the news in person in order to have an opportunity to ask questions or receive appropriate support.

### 4. Consent

1. I have information in my son's medical records regarding the matter of consent and that of being tested. On the [GRO-B] Dr J A J Williams, Consultant Paediatrician, Glan Clwyd Hospital, received a letter from Dr Lynne Ball, Consultant Paediatric Haematologist at Alder Hey informing him that; *'it was decided from the Haemophilia Directors Meeting that Cryoprecipitate was no longer to be regarded as safe as heat treated Factor VIII concentrate. There are presently studies involving the use of*

*specific concentrate for untreated patients which require close monitoring post infusion to determine whether or not these children will go on to develop non-A, non-B hepatitis, and in the long-term develop liver dysfunction. Obviously, once we have formulated a specific plan I will arrange to see the [GRO-B].*

2. In a letter dated [GRO-B] from Dr A J Williams, Consultant Paediatrician Ysbyty Glan Clwyd in reply to Dr Lynne Ball, Consultant Paediatric Haematologist at Alder Hey, Dr Williams concludes with the following question, *"One matter I am anxious to discuss with you in any case is the question of whether we should be deliberately looking for HIV antibodies or merely do this at the parents' request?"*
3. The following unsigned note is on my eldest son's hospital file dated [GRO-B] *"In the event of Factor VIII administration being required, it is VITALLY important for the question of serology for both hepatitis B and HIV to be discussed with whichever parent accompanies the child and the appropriate arrangements made with the Microbiology Department for the receipt of the specimen. NOTE that neither child has received Factor VIII or other blood products at the time of writing [GRO-B] so they need not be considered high risk specimens but clearly this should be discussed by telephone with the Microbiology."*
4. It appears from the many letters on file during the period between [GRO-B] and [GRO-B] that there was a period of confusion between Alder Hey Hospital and Ysbyty Glan Clwyd, Denbighshire regarding who was responsible for funding treatment for both boys. It would appear from a letter of [GRO-B] and the note from [GRO-B] [GRO-B] that any treatment plan was to include testing for virus contamination. My eldest son received his first treatment of



Factor VIII for an ankle bleed at the age of [GRO-B] in June 1991 his younger brother was treated in June 1994.

5. Regarding the issue of parental consent and the giving of adequate information on [GRO-B] a letter from the Consultant Haematologist at Alder Hey to our Paediatrician at Ysbyty Glan Clwyd indicates that we, as parents, had been informed of that prior to our sons being given Factor VIII they should be tested for hepatitis and HIV and then tested at yearly intervals. In 1994 a new Consultant Haematologist commenced at Alder Hey and regular joint clinics were arranged thereafter involving both Alder Hey and Glan Clwyd Hospital.

## 5. Impact

1. How to describe the impact of my brother [B]'s death? It was a difficult and terribly sad time giving birth to his two haemophiliac nephews during the period [B] was dealing with the huge implications of his own mortality and the concerns he would have had regarding the welfare and financial security of his immediate family. [B] told me about his HIV status in [GRO-B] [GRO-B] after the birth of my second son. He was very sad at the thought of his own failing health as his two nephews grew up, especially having the shared bond of them having haemophilia. To avoid unnecessary medical complications due to his physical vulnerability, during the next [GRO-B] years until his death in 1990, I had the added pressure to ensure we did not visit with any childhood viral infections as his weakened immune system started to break down. This was such an extremely sad period for not only his family but my elderly parents, my two sisters and our extended close family. [B]'s death had a big impact on his many friends too. In addition, I was hearing harrowing stories of the

experiences of other families we knew from the haemophilia and gay communities whose family or friends had been infected with HIV. Before he died [B] asked me to trust that Factor VIII would be safe by the time the boys may need it. They did go on to have it from 1991 and I was often very anxious whenever they received an infusion of Factor VIII as it always triggered thoughts of my brother.

2. [B] suffered greatly from the physical side effects of the treatments and the virus. It was difficult seeing a huge bear of a man disappear before your eyes. [B] was very affected by the whole disaster however his spirit stayed strong for all of us. Some comfort came from him being able to have his close family and friends nurse him at home until his death.

3. The devastating impact that [B] contracting HIV had on our private, family and social life is a thread that I hope that I have described in each section of my statement. We suffered worry, fear, sadness and the shock of realising the enormity of the impact over the years. I still have the faded yellow newspaper cuttings from the 1990's. The video recording of our father and mother, filmed in their home in 1990 just weeks after [B]'s death, being interviewed for the [GRO-B]  
My father fighting back his tears as he talks of his hurt, pain and anger at the scandal of the contaminated blood products and my brother's death. My mother's face pale with grief, both so brave, talking for [B] and his family, now he had no voice. They weren't going to keep quiet. I look back with pride at their courage. I have my brother's funeral leaflet and letters from [GRO-B] through to [GRO-B] to MPs and Parliamentary Health Ministers written in hope of some action, some recognition, of the suffering the scandal caused.

4. In conclusion, I would like to know, speaking as a young carrier as the time, if I could have been better informed or warned of the risks of viral contamination between 1980 and 1984. I would like to think that I may have considered either delaying my having children or perhaps giving more consideration to having the amniocentesis test. It is now my view and belief that both my children were at risk of receiving contaminated treatment between the time of their birth to the period when BLP started general issue of its new heat-treated Factor VIII in September 1985. I now believe that it was largely down to luck they were not infected.

## **5. Other Issues**

1. Documents which I have that might be relevant to the Inquiry's Terms of Reference: 1) Hospital records and 110 letters from the childhood medical records both sons. 2) My own GP records. 3) An article written by my brother in [GRO-B] following his [GRO-B] where he writes an article on [GRO-B] [GRO-B]. 4) A video recording of an interview with [B]s (our) parents recorded in 1990 for [GRO-B] [GRO-B] 5) Selection of replies from letters to MPs [GRO-B]

### Statement of Truth

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

Signed.....

GRO-B

Dated.....

26<sup>th</sup> February 2019