Witness Name: GRO-B
Statement No. WITN2441004
Exhibits: WITN2441005-WITN2441009
Dated: 1st October 2021

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7th June 2021. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, GRO-B will say as follows: -

1. <u>Introduction</u>

1. My name is GRO-B My date of birth is GRO-B. I am retired and I live at GRO-B

2. <u>How Affected</u>

1. I am submitting this Second Written Statement to the Inquiry along with:
    a) Letters and case notes from my own and both of my sons' health files between 1980 and 1994. These can be found at Exhibit WITN2441005.
    b) Various items of correspondence with Members of Parliament from GRO-B. These can be found at Exhibit WITN2441006;
    c) Publications and articles written by and about my brother

GRO-B: B. These can be found at Exhibit WITN2441007 and provide some insight into his great character and fortitude;

d) Correspondence with Dr Korn and Dr McVerry. These can be found at Exhibit WITN2441008; and

e) Letter from AJ Williams to D GRO-B dated 10th February 1984. This is exhibited at Exhibit WITN2441009;

2. I have permission from my sons to include their case records. However, they wish their names to be redacted. Both of my sons have Haemophilia A.

3. I am submitting these documents to provide an insight into my experience as a 'sister carrier' of Haemophilia A in the yearsbetween 1980 and 1994. My First Written Statement to the Inquiry provided details of a family history of haemophilia and how I was affected by giving birth to two haemophiliac sons during the early 1980s, at a time when my brother was infected with HIV from Factor VIII, resulting in his death in 1990. Watching the Inquiry, I feel that the impact on sisters who were carriers has not been fully covered as a specific group of people deeply affected by the impact of the scandal.

4. In February 2019, I provided my First Written Statement to the Inquiry. When I initially approached the Inquiry, I discovered that writing a statement as a carrier did not easily fit into the criteria at that time. I was advised by the Inquiry that I could write about how Iwas affected by my brother's death from HIV/AIDS, but it was unlikely I could write a statement focusing on my experience of being a carrier duringthe time. I did press my case and submitted a statement as a carrier. I went on to request my health records and those of my sons, to help me to go backand remember some of the details of the numerous doctor and hospital visits I undertook at the time. I am grateful to have an opportunity to share these documents with the Inquiry.

5. There are three major hospitals in North Wales: Ysbyty Bangor, Ysbyty Glan Clwyd, and Ysbyty Wrexham. In 1980 our regional Haemophilia Centres for adults and children were in Liverpool. As my brother was a patient of Dr. Korn, I wrote to him in 1980 to enquire about how I went about finding out about my carrier status. He started the process by referring me to Dr. B A McVerry, Consultant Haematologist at the Royal Liverpool Hospital.

6. In 1980 I was GRO-B years old and planning to marry. I was seeking clarification of my carrier status, in order to make an informed decision of whether I should consider having children. I had grown up with a grandfather and brother who had Haemophilia A. My grandfather, GRO-B lived an active life into his 80s and my brother B, also lived an active life despite GRO-B. I grew up with my brother managing his bleeding episodes with a combination of bed rest, bloods and Cryo treatments. I remember the discussions about the new Factor VIII treatments in the late 1970s which seemed so positive at that time. I had grown with the knowledge that my older sister by GRO-B years, had been told that a 'sister of a haemophiliac should never have children'. It was the optimism that grew from the development of the new 'life altering' Factor VIII that spurred me to be tested as a carrier in 1980. I have exhibited letters from Dr. Korn and Dr McVerry from 1980 to 1982 at WITN2441008 which confirm that I was a carrier.

7. I recall Dr McVerry discussing the options I had as a carrier. I was informed that if I became pregnant, I could access an amniocentesis test at 12 weeks. I could then choose to have a termination if the result indicated I was carrying a boy with haemophilia. I was informed that there was a significant chance of miscarriage due to the procedure at that time. These were the only risks that were discussed. Dr. McVerry did not caution me regarding any viral risks associated with the treatments available for haemophiliacs at the time. I recall discussing the benefits of Factor VIII with him. At no point were the issues around the danger of

hepatitis or inhibitors and the resulting serious long-term health issues discussed with me.

8. I cannot imagine that the numbers of potential carriers that were directed to Dr. McVerry were high in 1980. I want to know if any consideration at all was made by Haemophilia Directors to inform young carriers about the risks of treatment should they decide to have children. I must have been one of many across the UK who were carefully weighing up whether or not to go ahead and have children at the time. I have not heard any evidence that specific information and advice to potential carriers was brought up for discussion by Haemophilia Directors as the risks of viral contamination were becoming more apparent. Most comments have been made under the general term 'family support'. I feel there have been few references to carriers as a specific group during the Inquiry.

9. I weighed up all of the risks with my experience of living with a grandfather, brother and cousins with haemophilia who lived full lives, despite their bleeding episodes. I was influenced by the potentially 'life enhancing' properties of the Factor VIII treatment. I did give serious consideration to having the amniocentesis tests. However, in 1982 this was a difficult choice for me to make as I knew I would face opposition from my own parents and family at that time. I believe my brother would have found it hard to accept me terminating a male foetus because of his spirit and determination to live a full life with haemophilia at the time. At that particular time, it was not the norm to access counselling and I do not know if it was even available. I do not think I could really talk to anyone in depth and I take responsibility for the choice I made to go ahead and have children. However, I now believe that I made a mis-informed choice at that time. I was not informed about the known treatment risks by Dr McVerry.

10. I went on to give birth to two sons with Haemophilia A in GRO-B and GRO-B Letters and case notes from that period are exhibited at WITN2441005. They

map out my experience of being a carrier and a mother and contain letters from Consultants, various GPs, Directors of Finance, Personnel and Pharmacy services from the Liverpool Health Service. North Wales is a compact region with a long association with the Centres in Liverpool pre devolution. Doctors from the adult and Children's Centres in Liverpool were used to communicating with doctors in North Wales. I believe the Consultants knew the patients and families across the region. Only once is there a reference in the correspondence to an enquiry made (by me) about the emerging risk of AIDS in the case notes in a letter to my GP from my son'sConsultant Paediatrician dated GRO-B and exhibited at WITN2441009. I believe that the fact that the enquiry came from me, represents what was wrong at the time. The response to my question was 'although there was a potential real risk for the future, it was really rather unlikely at present'. I do not recall the exact words in the conversation, but I must have felt reassured to some extent, as I went on to become pregnant with my second son in GRO-B. A difficult fact for me to come to terms with, is that through family statements to the Inquiry, I now know that my brother was diagnosed with HIV in February 1984.

11. I understand that my brother's Consultant could not discuss his HIV status with me when diagnosed in February 1984. What I cannot understand is, why over those early years when the dangers of HIV infection were known to the Haemophilia Directors, no attempt was made to contact and advise carriers of the known risks that were presenting. Perhaps it was too late for me to have delayed or reconsidered getting pregnant with the birth of my firstborn son in GRO-B. However, I would have had a chance to have had made an informed choice before I fell pregnant with my second son in GRO-B. I gave birth to two vulnerable boys into, as one Centre Director put it in his evidence to the Inquiry, the 'maelstrom' years.

12. The impact the Infected Blood Inquiry has had on me has had been significant. The decision to become a Core Participant has involved addressing feelings, emotions and discussions that have remained unsaid

and locked away for over 40 years. Of course, I love my children, and cannot imagine a life without them. However, I have had to face my sons and explain that in my heart I know I should not have brought them into the world to face such highrisk and danger of death from HIV and hepatitis C at the time. The risks were confirmed by the Inquiry evidence in June 2021 revealing the high number of children contracting HIV and hepatitis C at Alderhey Children's Hospital in the 1980s. It is only by luck alone that they did not require Factor VIII until 1990. As a carrier, I have born the weight of personal guilt and not been able to speak to family members about it. It was so frightening and sad throughout the 1980s and 1990s to live through the media storms and hear of other sister carriers losing their sons, brothers, cousins, uncles, and grandfathers. The Inquiry testimony and heartache of the parents who did lose their children has been harrowing. The Inquiry process has been difficult to participate in. The legacy of guilt has run hidden and deep throughout my life as a mother of two haemophiliac sons born at that time. Had I been given the truth about the known risks, I may have delayed having a family, considered adoption, or considered invitro testing. I will never know. My one hope is that my GRO-B will have a more truthful and respectful experience as they grow up following this Inquiry. It is for their future that I welcome the depth of the Inquiry and I now have hope that future carriers have truth and full information as a basis for any choices they may have to make in their future.

Statement of Truth

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

Signed.... GRO-B

Dated........1st October 2021.