Witness Name: GRO-B
Statement No: WITN2767001
Exhibits: WITN2767002-4
Dated: MARCH 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

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

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B 1975 and I live at GRO-B I am by occupation a part time driver. I live with my wife GRO-B and our GRO-B year old son, GRO-B.

2. This witness statement has been prepared without the benefit of full access to my full medical records. I have a limited number of notes and records.

Section 2. How Infected

3. I was diagnosed with severe Haemophilia A at the Royal Free Haemophilia Centre in June 1977. This confirmed the prior diagnosis of haemophilia made in GRO-B Germany (where my father was stationed with the British Army).

4. I was treated at the Royal Free Hospital Haemophilia Centre under the care of Dr Goldman until the end of 1986 when we moved to GRO-B I was then treated at the Nottingham Haemophilia Comprehensive Care Centre at the Queens Medical Centre under the care of Dr French and Dr Dolan.

5. I am co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated blood products.

6. I refer to **Exhibit WITN2767002** being a copy letter sent by Dr Goldman to the Senior Registrar at the Nottingham Haemophilia Centre on 30th October 1986. I was identified as being HIV positive from a blood sample taken on 18th May 1985. Retrospective testing of a frozen sample from 1983 was negative. They had no samples from 1984.

7. I refer to **Exhibit WITN2767003** being copies of my treatment record circa 1980 through to 1986.

8. My parents recall being contacted by the hospital and asked for us to come in for a blood test. Being a haemophiliac I was used to needles and I do not believe that I would have given the blood test any thought. My mother says that she and my father received a letter from the hospital advising that they were HIV negative but that there was no mention of me in that letter. My mother rang the hospital and they said 'we think we need to organise an appointment for you to come in and talk to us'. I believe the subsequent appointment to have been with Dr Goldman.

9. I was only 9 years old. I do not remember much about the appointment but I have a vague memory of someone bending down to me and saying something about HIV in a corridor. I don't remember what was said. My parents talked to me and explained as best they could after the appointment that I had HIV. I do not think that my parents were given very much information or advice by the

hospital. They were told nothing about managing the infection. They said that they were warned to be careful when handling my needles and then they were just left to get on with it. My mother said it was like being handed a ticking time bomb as they were told by the doctors that I was unlikely to reach my 15th birthday.

10. I was not informed that I had HCV until some time in my late teens/early twenties I refer to **Exhibit WITN2767004** being a letter from my (limited) medical notes dated 6th June 1995, suggesting that I was told around that time. I was under the care of the Queens Medical Centre then. I do not remember much about being told or any of the specific details. It was just another problem for me on top of the HIV. It was the HIV diagnosis that occupied all my thoughts.

11. I have always been treated well at the Queens Medical Centre and I do not really have anything bad to say about them. My mother said that Dr Goldman was a nice lady but it was hard on my mother being left to get on with it without support. My father was with the army and was away on exercise a lot of the time. My mother had a very difficult time trying to deal with my diagnosis alone. I am an only child.

12. My parents and I were not made aware of any risks beforehand. Once we were told what had happened, we were given no help with literature, or anything similar.

Section 3. Other Infections.

13. I received a letter saying that I might be at risk of vCJD but a subsequent letter (dated March 2005) advised me that there 'is no evidence that' I received blood products from donors that had later developed vCJD and the risk was low in any event.

Section 4. Consent.

14. I believe there to be mention of Hepatitis B within my medical notes. I was not aware that I had been tested for Hepatitis B. I do not remember specifically giving consent for HCV (formerly known as non-A, non-B Hepatitis) testing.

Section 5. Impact

15. I met my wife GRO-B in 2002 and we married in GRO-B I had HCV clearing treatment in the form of weekly Pegylated Interferon injections and Ribavirin over the course of a year from 2003. GRO-B and I were, at that time, living with my mother. I experienced flu-like symptoms and suffered with chronic fatigue but I was told that the treatment had been successful and I cleared the virus.

16. I was given HIV antiretroviral medication in July 2005. I contracted shingles at that time and there was some concern that my immune system was low. GRO-B came with me to my appointment at the GU Clinic at Nottingham City Hospital (where I attend for HIV appointments) in March that year. We wanted to have children when we were married. Sperm washing treatment was discussed as a possibility but we were told we would have had to pay for the treatment privately.

17. The antiretroviral medication I was prescribed had few side effects except for weight gain (to my face), upset stomach and wind. I responded well to the treatment and the 3 to 4 tablets I was taking initially are now reduced to 2 daily. My CD4 levels have remained at undetectable ever since.

18. The emotional and psychological impact my HIV diagnosis has had on me has been immense. I suffer with anxiety and depression. I do not remember a lot of the detail about being told that I had HIV at that young age. I believe the gaps in my memory to have arisen through the mental trauma of having to live with such devastating news and that I have blanked out a lot of the information as a coping

mechanism. Referring again to the letter at **Exhibit WITN2767002**, I was extremely distressed and feared that I would soon die. The letter also states that we were counselled several times at the Royal Free but my parents do not remember any counselling at all.

19. As I got older, the information given to me about my diagnosis was even harder for me to accept. I listened to friends, friends' parents, family members and even teachers all talking about HIV/AIDS as it was shown on horrible adverts on TV designed to shock people. Life was hard, very hard, knowing that I might not reach my birthday or Christmas year after year. Every time I caught a simple cold I thought "this could be the end". My school years suffered being in pain with joint bleeds and having to have regular injections and time off school. I would ask myself time and time again 'why me?', 'how did this happen?' and 'how did the NHS allow this to happen?' I thought about ending my life several times throughout my teenage years. I remember the feeling of being on my own with this virus inside me that I didn't ask for and I didn't get from sleeping with someone. I was so upset and angry that I was infected by a trusted medicine that was supposed to help me live. It hurts me so much now just to recount what I went through at that time.

20. I remember an incident whilst at school during my teens when I went on my own to a dental appointment. I sat in the waiting area, waiting and waiting and I was made to wait until the very last appointment of the day. I had no understanding at the time of why I had been made to wait for such a long time. When I was finally called into the room, everything and every surface was covered with sheeting. The dentist and dental assistance had full length body suits on. I walked out of that place and ran crying to the bus stop. I cried all the way home on the bus.

21. My grades at school suffered. There are reports from teachers at the time saying I'm not paying attention and that I seem to be in another world. I took up smoking

a couple of years before I left school. I thought I might as well do what I like. My choice of career was restricted. When I left school, my father got me a job at Tool Company. I sold parts and spares over the telephone which, in hindsight, was a good distraction for me. I used to get home from work, get in my car and drive around with the music on and cry. That was my way of dealing with it.

22. My life and my parents' lives have been consumed with fear from by the day we were told of my HIV diagnosis. My mother feels responsible and carries a lot of guilt. I am changed as a person, mentally and emotionally. Not a day goes by where I don't think about it. I would have had a very different life had it not been for my diagnosis. Even though my CD4 count is at undetectable levels, I have been on antiretroviral drugs for the past 14 years and it is always at the back of my mind that one day the drugs might stop working.

23. Telling GRO-B that I had HIV was very emotive for both of us. One of my old friend's GRO-B parents moved to a house near the coast. GRO-B invited me, GRO-B and three other male friends to come over for the weekend. GRO-B and I had being "going out" for 12 months and everything was perfect. We had a separate room from everyone else. On the Sunday morning we talked to each other saying how much we like each other etc. I was desperate to tell her. She deserved to know. I did not know how to come out with it and whether she would take it badly but the time felt right. I also knew that once I told GRO-B we would have to deal with it, potentially, for the rest of our lives. I told GRO-B my situation that morning and it was one of the hardest things I have had to tell someone that I loved so, so much. Everyone had gone into the kitchen for breakfast but we were still in the room both crying. I explained how and when I was infected. GRO-B was naturally upset. We were going to all go to the coast that day but GRO-B just wanted to go home. Everyone thought we had broke up or had a falling out. I said "we are going home" and made a sharp exit to the car. We drove for an hour and a half home with not really saying anything. GRO-B cried the whole way home and I felt so bad. My now wife of 14 years is such a awesome person. I don't think I would be here now without her. She made my

life worth living and fighting for. She gave birth to my son and took such a gamble and for that I love GRO-B so, so much that words cannot describe.

24. Attending my appointments at the GU Clinic is very difficult. My anxiety levels are high. I always worry that one day the doctors will tell me that my levels have changed. Moreover I feel uncomfortable and on edge in that environment. It is degrading going into GU and sitting with everyone waiting for STI results. For a few years. I was allowed to sit near the back away from everyone but they have changed that now so I have to sit with everyone else. Everyone looks at each other, wondering what each of us is there for. I do not park outside and am on tenter hooks in case I see someone I know.

25. I have always kept my HIV and HCV status to myself out of fear of being stigmatised. I have never told my work colleagues that I have haemophilia in case they make the link. I very rarely visit my own GP surgery. I always use the Haemophilia Centre where I can. We know people that work at our local surgery and would not want them to know personal details about us. Even with confidentiality and data protection guidance, people do talk. I used to be a driver for a doctors surgery. I have witnessed the reaction of panic of a doctor to one of his HIV patients being sick on the floor. I had to turn away.

26. I have a GRO-B year old son, GRO-B, and my best friend and wife, GRO-B to think of. I am unable to get life assurance for my family. Our family home would not be secure in the event of my death as GRO-B would not be able to afford the outgoings and mortgage repayments. We are restricted in relation to where we can travel to for holidays. The price of travel insurance also makes it difficult to travel. It costs more than £200 for a one off two week holiday and if you experience any problems deemed to be associated with HIV or HCV you are still not covered.

Section 6. Treatment/Care/Support

27. My parents and I were not offered any counselling.

Section 7. Financial Assistance

28. My mother accepted a £20,000 compensation payment through the MacFarlane Trust in 1991. Ann, the Haemophilia Nurse at the Queens Medical Centre told us about the payment. My mother saw the payment as hush money. We thought it was not enough but they thought I would not live much longer after it anyway.

29. In 2004 I received the Stage 1 ex gratia Skipton Fund payment of £20,000 which helped GRO-B and I towards buying our first home.

30. We also received a monthly payment to include a discretionary top up payment. It is quite an invasive process as you have to send your bank statements in addition to your wage slips they are then looking at everything you spend your income on.

31. I have only ever applied for specific grants when there has been a real need. We have applied for window repairs and have had to get alternative quotes. We once applied for funds for karate lessons fo GRO-B We were asked why he wanted to do that activity. I would ask 'why shouldn't he?'

32. A few years ago, we applied for a grant for adaptations to our home to include a walk in shower and a kitchen to meet my needs. The grant for the adaptations was sought from the winding up reserves held by the MacFarlane Trust at that time.

33. GRO-B dealt with the application and spoke to Jan Barlow (the MacFarlane Chief Executive). GRO-B did not find her to be warm or compassionate. Ms Barlow commented to GRO-B that 'we cannot have people driving around in gold plated

cars'. We were compelled to go into a detailed explanation about the specifics to the kitchen to include appropriate seating and work surface levels to enable me to chop vegetables and oven fitted at accessible height.

34. It would appear that EIBSS are similar in their approach and cracks are starting to appear.

Section 8. Other Issues

35. There are no other issues.

Anonymity, disclosure and redaction

36. I wish to remain anonymous and would like my Statement redacted. I understand that this Statement will be published and disclosed as part of the Inquiry. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.. GRO-B

Dated.......14/3/2019.............................