Witness Name: GRO-B
Statement No: WITN2780001
Exhibits: WITN2780002-3
Dated: FEBRUARY 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 the GRO-B 1975 and I live at GRO-B GRO-B GRO-B, Birmingham, West Midlands GRO-B

2. This witness statement has been prepared without full access to my medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

## Section 2. How Infected

3. I have severe haemophilia A, diagnosed from birth. My mother is a haemophilia carrier. I am one of six siblings. My younger brother and one of my nephews are haemophiliacs.

4. I was treated at the Birmingham Haemophilia Centre initially at the Children's Hospital and at the Queen Elizabeth Hospital (QEH) in adulthood. I was under

the care of Dr Mann as a small child and then Dr Frank Hill until my teenage years when I was cared for by Dr Hill and another consultant Dr Williams, jointly. I was then treated by Dr Wilde at the QEH from the age of 18 or 19.

5. I was treated with cryoprecipitate from 1976 to 1980 and then with a range of Factor VIII (FVIII) products. I am co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) as a result of being given contaminated FVIII blood products.

6. I had a challenging upbringing. My parents are of GRO-B origin. My mother, in particular, speaks little English and she has never learned to drive a car. I learned to be self sufficient with my treatment and act independently of my parents from a young age. My mother (as the supervising adult) was supposed to administer my home treatment but I treated myself. I pretty much learned how to self-inject from the age of 4 years. I would still go for hospital treatment if the bleeds were heavy or painful. My mother would struggle in journeying to and from the hospital with several young children in tow and, as a result, I would catch the bus to and from the hospital on my own from when I was around 8 years old. I also spent a lot of time admitted to hospital having treatment. I had a lot of falls and was involved in a lot of rough and tumble.

7. I was just 12 years old when I was told that I had HIV. My parents were told of the diagnosis first. They were both called in to see my Consultant (Dr Hill, I believe) with an interpreter there present. My father did not usually attend the hospital appointments because he had to work. I have never had an in depth discussion with my father about my HIV diagnosis. We do not have that sort of relationship as it is not within our culture to talk openly about personal matters of this kind. I understand (from my mother) that he was angry and did not agree with the suggestion made by my Consultant that I should not be told. After a short period of time and given my direct contact with the Haemophilia Centre, my father insisted that I be told.

8. I recall the period of time between my parents knowing that I had HIV and being told myself. There was a sour atmosphere in the household. I had an inkling that all was not well for me. My mother suffered with bouts of depression. She was clearly very badly affected by the news that I had been infected with HIV because she was particularly down and subdued. I knew about the link between haemophilia and HIV/AIDS. HIV/AIDS was in the media and the 'Don't Die of Ignorance' campaign advert kept coming on television. I remember my mother once exchanging looks with me when the advert came on and shaking her head ever so slightly and knowingly at me.

9. I was told that I had HIV by Dr Frank Hill at an appointment with a nurse and a junior doctor present. He said words to the effect 'I am sorry to say that what you have seen on the television affects you, as you are one of the haemophiliacs to have received contaminated treatment'. I remember my response. I said 'And? ...' I was quite defiant and rebellious in my youth. I was used to my independence but I was shocked and not mature enough to process the news. Dr Frank Hill went on to explain 'You may feel well now but in a few years you will be unwell. You certainly will not see the age of 20'.

10. I was also told that I would not be able to marry or have a relationship with the opposite sex. I could not help but wonder why that mattered. I was going to die. There would be no point in trying at school. There was no point in anything. I took up smoking after that (at the age of 12 and have smoked ever since) and I thought I might as well do anything I want to. I was told that I had likely been infected for 3 or 4 years (in 1982 or 1983). I have relatively recently obtained my medical notes and records. They are incomplete and are not ordered chronologically. There are gaps in the notes and the notes for that time period (1982 to 1986) are missing. I refer to **Exhibit WITN2780002** being a letter dated 7th December 1993 from Dr Williams to Dr Wilde confirming that I had been exposed to HIV by 1983. I also refer to **Exhibit WITN2780003** being treatment

record sheets at that time naming Armour/Factorate as the treatment product of the time.

11. I was very specifically told that I was not allowed to tell anyone that I had HIV. I was told by Dr Hill not to tell *anyone*. There is a huge amount of stigma associated with HIV/AIDS in the Asian Community, even now. If anyone knew, my family and I would be shunned and be left at risk of attack. It would be assumed and believed that I was culpable for my condition notwithstanding the clear culpability of the State. I do not share or talk about my HIV and/or HCV status to anyone. I do not speak of it to my parents and my younger siblings do not even know about it. I carry a lot of shame and guilt. It has been difficult for me to have no-one to talk to and share my fears and concerns except the health professionals looking after me. Dr Hill said that I could not even tell my fellow haemophiliac friends. In retrospect I believe it suited him that we were unable to confer. I had been in and out of hospital so many times that it felt like I had spent more time in hospital than at home. I had formed close friendships with my fellow haemophiliac patients. I would look at my haemophiliac friends and wonder if they too had been infected. They would look well enough but we were not allowed to talk to them about the infection. They were probably thinking the same of me.

12. The manner in which I was told I was infected and how I was treated throughout my childhood was appalling. I felt like a commodity. When I was 15 years old, a hospital nurse saw me kissing a girl. I was called into the office by Dr Hill with two nurses and a junior doctor present. They demanded to know what I thought I was doing and warned me that love bites were a mode of cross infection. I was again defiant and I said 'What are you talking about, why are we discussing love bites?' I was not interested in the lecture and they said 'If you are not going to listen, we need to give you some condoms'. The experience was really

uncomfortable and demeaning. I said 'I know my limits and I do not need any condoms'.

13. I found out that I had HCV when I transferred, as an adult, to the QEH after I had turned 18 or 19, in 1994. I had no idea at all that I had HCV until my very first appointment with Dr Wilde at the QEH. Dr Wilde, in turn, had no idea that I was ignorant of the diagnosis. He introduced himself and started to read and recount the content of my medical notes: 'Haemophilia A 0%, problems with neck and back, HIV, AZT treatment, Hepatitis C.....' I interrupted him and said 'Hang on, what? say that again' He repeated 'Hepatitis C'. My next question: 'Since when?' It was as if a bombshell had exploded. Dr Wilde was shocked that I had not been told and so was I. I had, again, apparently been infected since the 1980s. The doctors I trusted, particularly Dr Williams, who was far more personable than Dr Hill had not told me. I was distraught and I still feel betrayed. I could scarcely believe that Dr Williams would keep that information from me.

14. After the meeting I went straight to the Children's Hospital looking for Dr Williams and I was told that he was not around/unavailable. I recall speaking to the Social Worker that I knew there called Mike and asking him 'How dare they not tell me?' Mike said 'I don't know but be careful how you tread. Your (younger) brother and nephew are getting treated here'. I took that as a veiled threat or a warning to me from someone I assumed knew what Dr Hill and his team capable of. Dr Hill had a reputation for being arrogant and vindictive. I have since heard reports of Dr Hill refusing to treat patients who have been critical of him. I do not know when the doctors knew about the HCV but they should have informed me as soon as possible. I received very little support from my GP in relation to the matter. His view was that instead of being disgruntled, I should in fact 'be grateful' for my treatment. I have since transferred to a different GP surgery.

15. After the incident, I spoke to my father and informed him that I was now HCV positive and had not been told. I was looking for some sympathy and support

from my father. It was the only conversation we have ever had about me being infected with contaminated blood. My father was intimidated. He expressed worry and concern about my younger brother and nephew and told me to 'leave it'.

16. I have seen a letter from Dr Wilde to my GP somewhere within my notes specifically referring to that (our first) meeting. There is no mention of my lack of awareness of the HCV diagnosis and my frustration at learning about it for the first time at that first meeting, which I find unbelievable.

17. My parents and I were not given any information or advice beforehand about the risk of me being exposed to infections from blood products. We trusted the doctors and were left shocked when we learned I was infected.

## Section 3. Other Infections.

18. I have been informed that I am at risk of vCJD, having been treated with the same batch of FVIII product as someone found to be infected with it. I understand that a confirmed diagnosis can only be made upon death so I will never know if I have it or not.

19. I refer again to **Exhibit WITN2780002.** It would appear that I was infected with Hepatitis B and had become immune to it by 1982.

## Section 4. Consent.

20. I was clearly tested for HIV and HCV without knowledge and consent and without my parent's knowledge and consent. I had countless hospital appointments as well as long periods of hospitalisation. Blood was taken from me on very many

occasions. I was never told what the tests were for. I assumed it was for monitoring and treatment purposes.

21. I also believe that I was treated with a variety of FVIII products for research purposes. I believe Dr Hill and Dr Williams knew and accepted that the use of the FVIII carried risks as did the Head Nurse at the Children's Hospital, Marion. I believe that I was treated with FVIII to see what would happen. English was not the first language of my parents. My mother suffered with depression (and has since been diagnosed with bi-polar). I was a vulnerable child often attending the Haemophilia Centre on my own. I was a sitting target, used like a guinea pig.

## Section 5. Impact

22. The physical and mental impact of being infected with HIV and HCV is enormous. I have suffered with a variety of associated conditions, ailments, infections and treatment side effects that have ravaged my health and are further complicated by my haemophilia and all the medications and heavy pain killers prescribed. It is difficult if not impossible to identify where and how they each cross over and to tell which is caused by which. I have been left suffering with chronic depression, anxiety and chronic fatigue.

23. Within the last 6 or 7 years I have had very serious physical issues involving major surgery on my neck, spinal chord and elbow leaving me incapacitated and in unbearable pain. The elbow operation went wrong, requiring further surgery within 4 weeks. Ever since then I have had swelling to my hands and ankles and the hospital has done numerous tests, increased and changed my medication but to date no-one can pinpoint what has happened. I am drowning physically and mentally. I am an emotional wreck.

24. Up until 6 or 7 years ago, all health issues were dealt with at the Haemophilia Unit at the QEH. We were introduced to the main GU Consultant, Dr Manavar,

and he was due to attend at the Haemophilia Unit for our appointments due to the sensitivity of the HIV situation, however, this was not the case. Other patients and staff were just as surprised that we then had to go to the GU Clinic to be seen there. Because of the fear and stigma that I worry about in others finding out about HIV I have become paranoid about being seen there and in relation to how others are looking at me. I felt passed from pillar to post in different environments. I found myself having to repeat myself to various members of staff about issues very personal and sensitive to me.

25. In August 2016 I was admitted for my neck decompression surgery. Despite my medical notes stating 'CONFIDENTIAL', the ward doctor breached this by closing the curtains (on our bay of 4 beds) and questioned me about my HIV and HCV status. After this my fellow patients stopped talking to me in the same ward. I belt belittled undermined and ostricised and degraded. I complained to the Ward Matron but nothing changed and no apology was offered.

26. I had AZT treatment at the age of 15 or 16 to treat the HIV. I have suffered with neck and back problems from a relatively early age and was prescribed steroids that I was taking at the same time as the AZT. I came off the AZT because it did not seem to be improving my health. There was a great deal of uncertainty as to whether my neck and back problems are HIV related (as referred to at **Exhibit WITN2780002)** and/or related to haemophilia. That uncertainty remains to this day. I had many long stays in hospital at that age. It was a traumatic time for me. I suffered with anxiety and depression, thinking about my death which I thought was imminent. Some of my hospital friends passed away. I knew why they had died but we were not allowed to speak about it.

27. I have cirrhosis of the liver. I finally cleared HCV with a combination of Harvoni and Ribavirin at the end of 2016 after a previous unsuccessful attempt at clearing it in 2003, involving the use of Interferon.

28. The first attempt at clearing treatment in 2003 had to be aborted six months into what had been intended as a 12 month Interferon trial. I was injecting myself every week with Interferon and the effects would knock me out for four or five days. It was insane. I couldn't get up. I am very stubborn and was determined to see the treatment through to the end but the side effects were terrible. I had severe headaches, I felt sick, I had sweats, shivers and flu–like symptoms. The treatment had a terrible affect on my mental well being. I had awful mood swings, strange thoughts and brain fog.

29. No further treatment became available that did not involve me having to take more Interferon and I could not go through the same side effects again.

30. I read about the Harvoni clearing treatment in the newspapers. The treatment was never raised or discussed with me by my doctors. When I attended the Liver Unit for my appointment, I asked the doctor about the treatment and I was told that I could not have it. I was told Harvoni was available on the NHS, but not available on the NHS *for me*. I found myself having to argue my case. My Liver Consultant at the QEH is Professor Mutimer but I was seen by another member of his team. I asked for Professor Mutimer by name and another doctor came to talk to me. I had to insist upon seeing Professor Mutimer and refused to leave until I saw him. I said 'Professor Mutimer is on my appointment card and I am going nowhere until I have seen him'. It was a stressful experience for me. After thirty minutes Professor Mutimer appeared and promised that I would be started on the treatment within 12 months. I was told that there was a 90% success rate.

31. After one week my viral count dropped from millions to hundreds, then hundreds dropped to eighty, and then it dropped to undetectable. It stayed like that until I finished the full course. I then waited a further three months to see if it stayed undetectable, which it did. It is a stressful process waiting for results. My liver is

still cirrhosed. The damage cannot be reversed. I attend regular ultrasound and fibroscan scans. I continue to suffer with nausea and bloating.

32. The psychological strain is unbelievable. I carry so much guilt and shame. My mother lost her (haemophiliac) younger brother to a bleed when he was 8 years old. They were close. My mother mental health deteriorated after my HIV diagnosis. She has been diagnosed as having bi-polar and has been sectioned under the Mental Health Act on two occasions. My relationship with my father has suffered. I feel like I have let him down. I am not the son he wanted. I would have had a totally different life had I not been contaminated with HIV and HCV. My father recently had a quadruple heart bi-pass. My infected status is taboo and I cannot talk to him. We do not see eye to eye and our relationship is strained.

33. I was married at 22 years old but the marriage ended as the impact of the infections took its toll. My wife wanted children and I was against it. I would not have been able to forgive myself had I passed the viruses on. From the age of 30 the cracks had started to appear. It was hard to carry on like nothing is wrong. I had lost a lot of friends. I could not understand why I was still alive compared to others that had died and was looking for differences between us. I was not looking ahead to the future; I was just living each day waiting for death to knock on my door.

34. I ended up in another relationship and, at the age of 41, we got engaged in March 2016. My fiancé, moved to Birmingham for a short while with her child. Within a few months I found out that I needed major surgery. I feel frustrated that I had found a suitable partner but was struck down with another life changing operation. The stress of the surgery and the continuous deteriorating health took its toll on the relationship and we amicably split up. We still speak but that relationship was also seriously compromised. I also had no libido due to my

medication, I had mood swings and just too much to contend with physically, mentally and emotionally. It was terrible. It affected her in a big way.

35. I have had concentration and brain fog issues since my HCV clearing treatment back in 2003. Last Bank Holiday August I was hospitalised with a suspected stroke, later ruled out. The left side of my face was affected. A possible diagnosis of bells palsy has been suggested but they believe it could be linked to HIV. Ever since, my speech gets stuck and I forget things. I have failed a HIV memory test and I have an appointment in April to investigate the matter further. I have had suicidal thoughts that I would not act upon because of my faith.

36. Two of my nieces in their late teens saw a letter/envelope from the MacFarlane Trust and googled what it was. They were very upset at discovering that I had HIV and begged their mother to assure them it (my diagnosis) was 'not true'. When they spoke to me, we had a difficult but very touching exchange. They said that I was the least deserving person they knew to have been given the medical issues that I have. They are very loving and caring.

37. In terms of education and work related impact, I spent significant proportions of my schooling whilst in hospital. I was told that I would not see the age of 20 when I was told that I had HIV but I have not been up to working in any event. Ironically, I wanted to be a doctor when young. I was quite adept in administering injections and had no difficulty in finding veins (my younger brother and, on one occasion, a fellow hospital patient) when some of the junior doctors were known to struggle.

## Section 6. Treatment/Care/Support

38. I have had problems in obtaining treatment. I was referred to an orthopaedic surgeon at the QEH by Dr Wilde for an operation on my right elbow a few years ago. I was referred to a professor and he referred me on to a surgeon in Liverpool because of my 'health issues'. I was in Liverpool hospital for three or four weeks. I came back for a week, but I then had to go back to Liverpool for more surgery as they had made my elbow worse. Dr Wilde said 'I hope you do not think I am to blame for that' and I said 'Well you are slightly to blame as you referred me'. Dr Wilde tried to tell me that the Royal Orthorpaedic do not do elbow surgery. I knew that was not the case because I knew others that had had it done there in Birmingham.

39. I have had some counselling but not much. I found it difficult. I feel very let down by everybody.

## Section 7. Financial Assistance

40. In 1991, I received a lump sum payment of £20,000 through the MacFarlane Trust (MFT) as a settlement payment. My father took control of my finances and signed a waiver. I had no choice in the matter. I thought that no amount of money could compensate me and I only had a few years left in me any way. The money was invested into the house I live in now. It was occupied at first by my sister for a few years until I moved in.

41. I received a grant of £20,000 from the MFT last year when they were running down the funds and inviting applications. My house needed opening up and substantial adaptions to meet my physical needs. The £20,000 helped but was a relatively small proportion of the over all cost. I later found out that the balance of the funds held by MFT were in fact passed over the Terrence Higgins Trust (THT). That Trust knew nothing about the matter when I contacted them. I eventually spoke to a Supervisor who said she was unable to do anything as yet with the money. A further grant before it went to the THT would have been

useful to me given the work I needed to complete on the house and I would have been left in less debt.

42. I received the Stage 1 ex gratia Skipton Fund payment of £20,000 in 2003. I received the £50,000 Stage 2 Skipton Fund payment in 2016. I believe that I was entitled to that payment much sooner than 2016 but I knew nothing about the qualifying criteria. Dr Mutimer, was on the panel of the Skipton Trust but said nothing to me despite clear evidence of liver damage.

43. I would have been completely unaware that I was entitled to a further payment had I not been told by another patient that you qualified if your FibroScan reading was in excess of 14 kPa. I could not at that time remember what my FibroScan reading was but I knew it was high.

44. I went back to the Haemophilia Unit to ask about it and I was told that I did not qualify. I insisted upon completing a Stage 2 Skipton Fund application form. They were reluctant to give it to me at first. Once I had completed it I handed it back to one of the Liver Unit nurse to complete her section. Four weeks later I was informed that I was entitled to the Stage 2 payment. I was then entitled to additional monthly payments which I started receiving. I feel very let down by Dr Mutimer. I do not understand why I was not assisted in making the application. My FibroScan was 21 kPa in January 2011 and had further risen to 37/38 kPa by 2013.

45. EIBISS are very difficult to deal with. It is like trying to get water out of a stone. There are so many questions and criteria specifics to deal with, without much chance of success. I applied for funding for a mobility car but was referred to the Birmingham Mobility Charity for the funding or a letter of refusal (which they refused to provide). I no longer bother asking for help.

46. EIBSS report that the payment system is devised to ensure that those infected will not be worse off than those affected. However the scale for the additional discretionary top up payments is weighted in favour of affected as the annual discretionary element for infected claimants in my income bracket is £362 and £917 monthly for affected claimants. It is the only element of my EIBSS payment that I am compelled to declare to the DWP. Moreover my parents were affected and never had support. I was just a child and my parents were deeply affected in every sense of the word. They felt responsible as they were powerless to protect their own child. Much has been said about 'affected' partners but 'affected parents' are equally as important. This is all contradictory and unfair.

47. Finally, I found out last year that in 2009 there had been a successful litigation in the USA open to litigants world wide. The pay-out was either $33,000 or $37,000 per litigant. Nobody told me about it. I am again disappointed that the Haemophilia Society failed to tell me about it. I made several phone calls to the requisite Attorney (Leiff Cabraser Heimann & Bernstein) in the USA but I was too late. I was told to make enquiries with other Attorneys in the USA but was never able to find one and drew a blank there.

48. From my knowledge, sufferers living in the Republic Ireland received an average settlement of £600,000 each. This is a lump sum in addition to receiving Government backdated schemes annually.

## Section 8. Any Other Issues

49. Since this Inquiry has come back into the limelight, I feel angry, withdrawn, reclusive feel that my whole future has been ruined by the system and benefits organisations. I have so much red tape to cut though before you can make any kind of claim. I am sick and tired of continuously having to explain to doctors and explaining myself going through PIP, ESA and EIBSS to justify my deteriorating health. At times I am made to feel like I have to beg for what I am entitled to.

50. I am staggered to learn of the amount of money companies made from the dirty blood or shall I say *from us*. Where is the Justice? I believe that it is now pay back time for us. There are approximately 200 left of us alive having been co-infected with HIV and HCV and numbers are still dropping as we speak. We should be looked after first; compared to the others affected. We do not have any choice and for whatever reason we are still here, a small number of haemophiliacs. We should see justice done and it is very important that we have financial help right now and settlement after the Inquiry.

51. I was given a life sentence when I contracted HIV and HCV. Those that have lost their lives were murdered.

## Anonymity, disclosure and redaction

52. I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry. I wish to give oral evidence.

## Statement of Truth

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

Signed GRO-B

Dated 26.2.19

## MEDICAL SUMMARY

**(This summary is not intended to be exhaustive but sets out some key points in the records referred to in the Statement)**

This witness statement has been prepared without the benefit of access to my full medical records.

| | |
|---|---|
| 17.01.2011 | FibroScan today measures 21 kPa with 100% success rate *(letter Dr Wilde to GP)* |
| July 2013 | FibroScan reading of 38.5 kPa *(letter to GP dated 15/07/2013)* |
| Aug 2013 | FibroScan 38 *(letter Dr Elsharkswy to GP dated 11/06/2015)* |
| 24.11.2015 | FibroScan score 37 kPa *(letter Liver Unit Sister to GP dated 02/12/2015)* |