Witness Name: GRO-B
Statement No.: WITN3908001
Exhibits: Nil
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 November 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1964 and my address is known to the Inquiry.

2. I can confirm that I have chosen not to have a legal representative with me at my interview with the Inquiry Investigators on 28 November 2019 and that I am happy for the Inquiry team to take my statement

3. I intend to speak about how my life has been impacted by contracting HIV. Particularly, how I was infected and how this disease, and its treatment, affected myself and my relationships.

Section 2. How Infected

4. I was infected with HIV in the latter part of 1984, aged 20, when I received a blood transfusion at Royal Victoria Hospital, Belfast (Royal Victoria). I was hospitalised after a car accident just outside GRO-B where I was a serving soldier. I went through the windscreen, fracturing my skull from above my eye and around to the back of my head.

5. The only thing I remember of my hospitalisation is waking up in hospital with a bag of blood hanging over my head. I recall noting that it was 'O' not 'O+' and telling the nurse who reassured me this was not an issue as 'O' can be used for all blood types.

6. Due to the urgency of the operation, I did not have the chance to consent to the transfusion, nor was I informed of any potential risk of infection.

7. Afterwards, my brother, the head of GRO-B at the time, informed me I had lost a lot of blood and had needed a transfusion. It was three weeks before I had recovered enough to leave hospital and go to GRO-B to be with my parents and recuperate. It took a while to get settled; both body and mind.

8. I discovered my infection 13 years later in 1997 when I was diagnosed with Stage 3 AIDS at the Royal Free Hospital, Camden (Royal Free). This diagnosis followed years of illnesses, which I will describe below, culminating in my being so unwell I had to crawl along the side of road on my hands and knees before arriving and collapsing on the floor of A&E. I was so weak I could not even make it to a chair.

Section 3. Other Infections

9. I also contracted Hepatitis B as a result of my infection.

Section 4. Consent

10. I do not remember being tested for HIV when I was admitted to the Royal Free in 1997.

Section 5. Impact

Ill health before diagnosis

11. I was very ill for a long time before my diagnosis, but refused to acknowledge it.

12. Around two years after the accident, I left the army and moved down to London where I got a job in a security systems company, earning enough to achieve my goal of getting on the property ladder. I was entirely focussed on earning enough money to pay off my mortgage, so much so, that I could not afford to acknowledge some very serious initial signs of my infection.

13. In November 1998 I was made redundant, as the company shut down. I worked until the moment the final piece of furniture was removed. Soon after, I got another job in security, working for Sears. That was when things started becoming strange.

14. I was very tired and suffering daily nose bleeds, which I put down to the stress of working a seven day week, without breaks, in a constant drive to pay off my mortgage.

15. My health problems began to accumulate. I was suffering constant headaches and leg pains. Again, I made any excuse to myself that I was OK.

16. My cognitive ability and emotional stability were breaking down as well. In addition to forgetfulness and tiredness, I was beginning to get snappy with people, which is not like me. I had become quite abusive, but could never remember it as it was so out of character for me.

17. One morning, I turned up to work in my dressing gown, an embarrassing incident, which was eventually presented to me via camera footage. I did not even recognise myself in the video.

18. These volatile episodes and strange behaviours led me to lose my job. The day I was fired my boss asked me if I was alright. She was concerned, as the last person she had seen act like this was diagnosed with AIDS, But I didn't even have time to go to the doctor.

19. I am gay but I had abstained from all sexual contact after seeing the frightening gravestone advert in the mid 1980s. I never thought I could possibly be HIV positive.

Health breakdown and diagnosis

20. After losing my job my health deteriorated further. In July 1996 I decided to visit my brother in Texas. GRO-B I was meant to stay for three weeks but I was so ill, I left after one. My nose did not stop bleeding the entire time, but I attributed this to the heat.

21. When I returned, I began working at GRO-B near GRO-B as I needed to maintain my mortgage payments. My office was only a mile's walk away from the Rail station, but every day it took longer and longer to walk there. I had to throw my feet out at every step. From my first day I suffered nosebleeds, headaches, blurred vision, and sensory damage in my fingertips. This was so severe I would hold things till I 'throttled' them.

22. Three months into my probation period my manager told me they were letting me go, I thought, at least now I can only get some sleep.

23. I returned to America in a vain attempt to relax. This proved impossible as I was developing night sweats so severe that I had soaked the bed. My brother got his personal doctor at the ranch to assess me and he said whatever I had, it warranted me returning to the UK to get treatment immediately.

24. On my return to London, a close friend who had seen me only the month prior, commented that I had lost a lot of weight. In fact, I had shed one and half stone in three weeks. I attributed this to my brother's vegetarian diet, I was doing anything to avoid the inevitability that I was seriously ill. It was only on reflection that I realised I had been unwell for years.

25. I attended my GP who stated that I was only run down and suffering from exhaustion and given vitamins to help. After a further visit on the same day demanding to go to hospital he reluctantly agreed.

26. Once admitted, I was so tired I barely knew what was going on. People were coming in and out constantly, taking tests I barely registered. My brain was going at one mile per hour. What I do remember is being startled into attention by a doctor telling me, "if you're still with us in the morning we can start treatment".

27. I was taken into a private room soaked in sweat and so weak I could not lift my arms or walk, talking was also very difficult. I remember just wanting to be at home, in my flat, but I had to give in to the overwhelming exhaustion.

28. When I woke up, I saw someone approaching the foot of my bed. I barely registered when I heard them tell me I had Stage 3 AIDS. I was left there wondering if he had got the wrong person. Later, I was told to get my affairs in order, after this, I was left completely on my own.

Physical suffering after diagnosis

29. The weeks and months after my diagnosis felt like a sped-up film. I was struck down with so many afflictions simultaneously they begin to blur into each other. One day was like the next, what I do recall vividly is the never-ending drawing of blood.

30. My Legs and torso were covered in lesions which I took to be bruises. I reasoned to my doctor that I must have walked into my coffee table and doors at home. He told me, no, they are a symptom of Kaposi's Sarcoma, a rare HIV associated cancer. The Pneumonia condition left me breathless, as though someone was inside me squeezing my lungs. This was one of many health problems.

31. I stayed in the Royal Free for three months and whilst there I suffered a litany of symptoms. My doctor came in and listed everything wrong with me: blurred vision, diarrhoea, constant tiredness, swollen lymph glands, high temperature, Encephalopathy, depression, Pneumonia, severe weight loss, mouth sores and

neurological damage in the legs. This was further exacerbated by my co-infection with Hepatitis B.

32. I was given a considerable amount of drugs but I don't remember them. Ones I do remember were Ritonivir and AZT plus some others. I lasted about two weeks on these first incarnations, but had a bad reaction. I ended up going through 15 or 16 variations of medication, taking about four months to get the balance right. The side effects were debilitating and made me feel sick, plus some of the medications enhanced the hallucinations I was already experiencing.

33. I was given an exercise bike to try and regain some of my strength while in hospital. My time in the army taught me to assign myself objectives, so I set myself the mission of getting up onto the bike. On my first attempt, the physical strength just wasn't there. It took four days to even get out of the bed. The first two times I had to be picked up off the floor. The bike was moved closer to me and eventually I was able to get up on it using every item available to help me move towards it.

34. Another memory from that time that has stuck with me was seeing a woman, also suffering from AIDS, who was so thin she scared the life out of me. Then looking at myself realised I looked the exact same and was completely skeletal.

Mental suffering after diagnosis

35. The physical weakness and side effects from my treatment were compounded by an overwhelming feeling of isolation and fear that I would soon die.

36. My condition was initially so dire that the doctor told me to get my affairs in order, so I called my parents in Ireland with the phone heavy in my hand. My words were coming out letter by letter, in response, my mother gave me some strength. She told me to be strong and to do what the doctors tell me. I asked if they would come to see me, they said no, but that they were thinking of me. It was hard to hear but I reasoned it may be expensive to come to London.

37. Whilst I was on the phone they moved my room and the change threw me off. I began to have extreme hallucinations and thought people were coming to strangle me. I yelled at the lady who was delivering my food because it all tasted like petrol,

and in my mind, this proved that they were all in on it, the doctors and nurses, they were trying to kill me.

38. The hallucinations were getting worse, so a nurse from the Ian Charleson Clinic came up to see me and we spent quite some time talking to me and calming me. He told me the reason the food tasted strange was because my taste buds were shot, not because I was going mad. It finally felt as though I had someone actually listening to me.

39. At the same time, I was wondering if anyone in my family was going to come and see me. After three weeks in hospital, I had family members calling me up asking who I was going to leave my house to.

40. This distance was only emphasised when I arrived home from hospital. I remember it was around the same time Princess Diana died. Soon after, I was told my mother had died and blamed myself completely, thinking it was the stress of my illness that killed her. Even though I was advised not to attend, I was adamant I would be at my mother's funeral.

41. The funeral was a culmination of the sadness, distance and tension my diagnosis triggered. Even though I knew, to a degree, I was not accepted by my family, I could see that my mother had tried to express her love in her own way; People were aware of my diagnosis and sympathetic but All the same, they would not shake my hand or even stand near me at my own mother's wake.

42. Soon after, I 'crashed' mentally. I remember laying out all my prescribed medication and being completely overwhelmed. I thought, I have killed my mum, so took all the tablets, every last one. It took half an hour straight.

43. My neighbour found me unconscious and called for an ambulance where I was then taken back to hospital. The HIV Clinic was not told until three days later. In response I was given a counsellor, which was fine, they were there to listen, but my mental state had deteriorated so severely that simply talking was not going to alleviate much.

44. I returned home and was confronted once again with a huge pile of medication I could not cope with this and still wanted to take my own life. I walked into the kitchen

and put my head in the oven. My Neighbour again found me and had me returned to the hospital.

45. None of the people I needed, were available to me as in my family or friends, I felt completely alone. At the early stage of my diagnoses I was so cut off that the any reprieve from complete isolation was memorable. There was a neighbour, a retired nurse, who was HIV positive, he saw me and recognised that I had Aids . It was only with his help that I could accept I wasn't responsible for my mum's death or for the fact I had Aids.

46. I received help from the strangest of places, but not from where I needed it most, my family. I was even told by a family member that I may as well be already dead.

Physical side effects of treatment

47. I have endured countless drug combinations since my diagnosis; all of which have side effects. Some stand out as particularly severe. My initial round of AZT rendered me so anaemic I needed another blood transfusion.

48. A few years ago, I began T20, an antiretroviral which I had to self-inject into my legs, thighs and stomach. The liquid burned under my skin and sites had become so scarce my partner, GRO-B had to administer the drugs for me, risking pricking himself. Even though the drug itself was very effective, I could not stand it any more and had to be put back on something I could take orally.

49. A few months ago, I stopped taking my medication and was told by the doctors that as soon as I miss even a single tablet, the body starts to fight back. The doctor at Queen Elizabeth Hospital told me this was the last set of tablets available to me as I had used all the others, and if these do not work I would die.

50. I was also informed at this time, by the Hospital pharmacist that the medication I was missing, cost up to £1000. I have always paid attention to things in monetary terms so this made me appreciate how diligent I need to be.

Mental side effects of treatment

51. My condition was so severe that I have been on several drugs trials that are so new they do not even have a name yet.

52. One trial drug that I cannot remember the name for, made my already persistent hallucinations worse. I was told not to watch TV an hour before taking the medication. What I was not told was if you do, you will feel as though you were part of them. I was also talking to people who were not there. I quickly made the decision not to take them any more. I was moved onto another combination, which, whilst tasting like seaweed, was an improvement.

Stigma and personal life

53. Since my diagnosis I have felt isolation and shame I have been made to feel insignificant. Even when attending my mother's funeral, people would wave at me from across the room rather than approaching me. I have a large family and the separation from them is acute. For example, I was only told last year through a Christmas card sent to my Fathers address was returned stating that my dad had died in 2002. I do not know whether any of my family members are still alive.

54. Even something as simple as going to the dentist is an ordeal. In GRO-B there was a specialized dentist but when I moved to Birmingham, the dentist refused to see me, even though he is legally obliged to. I was sent to the hospital where I was asked more questions about my HIV than my teeth.

55. It was my HIV support group that helped me through those awful first years, a comfort I sorely needed as many of the programs offered to HIV patients inflicted more pain than they treated.

56. In the early years of my recuperation, from 1999-2008, I recall going to a clinic in GRO-B for massage and physio and being told by the nurse not to share facecloths. She would even wipe down the pamphlets the moment I put them down and was always using rubber gloves.

57. Even now, I fear bleeding in public as it means revealing my HIV status. As some would and have backed away from helping me.

58. My partner is a great support, (GRO-B who I met on a chat line while I was starting treatment.) I was up front with him from the start about my condition, he was unfazed. Moreover, he was interested in my treatment and my life. He asked me to call him back the next day so I could have someone there with me while I was taking my medication. We have been together ever since even though we have a non-sexual relationship.

Employment

59. The effects on my career and financial stability have been almost incalculable. I have not had a job since my diagnosis and have had to live off unemployment benefits for almost 20 years. My employability is completely spent.

60. Even now, with a supposed shift in attitudes, when I am asked why I have been unemployed for so long, and I tell the interviewer it is because I have been ill and live with HIV, I never hear from them again.

Financial effects

61. Beyond being unable to work, I also lost my home. In 1999 I got a letter from the bank to say that I had not paid my mortgage but I knew I had taken out payment protection insurance. When I went to claim, I was told 'no' as I am HIV positive. When I looked at the microscopic print of my policy I saw it did not indemnify me for HIV/AIDS.

62. I was advised to take it up in court and the bank was found to have acted unreasonably. They were made to cancel the PPI and reduce the mortgage. This helped temporarily, but I was still under so much financial stress.

63. I eventually went on unemployment benefits, but could only pay the interest on the mortgage. It had got to the stage where I had two mortgages for the one property and it all became too much. I decided to sell in 2008. My property was a housing association home ownership scheme; I rented half and owned half. The housing association made me wait a year and half so they could get the bottom price, so I lost £20,000. I just needed to move out and move on.

Section 6. Treatment care and support

64. Many of the experiences I have described have been when my health was critical, so I cannot remember in too much detail. Instead, I will describe the brief moments.

65. I cannot fault the Royal Free staff. The doctor who treated me after my diagnosis was brilliant. He did not only want to know about my illness, he wanted to know about me. He asked about my home life, how I was doing, even whether I had enough furniture. It meant a lot to me and he ended up being my 'go to' person.

66. It was also prompted by the doctor at the Royal Free to think about how I was infected. I was asked to go back ten years. I knew I had not been in sexual contact with anyone nor ever injected anything. Being in the army, tattoos were the norm, I did not want this and never had one.

67. I was then prompted to think it may have been from the road accident. My doctor said it would be very difficult to prove that I got infected during my time at the Royal Victoria Hospital in Belfast after this.

68. I Also remember that during the 1980's there was an overriding belief that AIDS had not reached Northern Ireland.

69. Another instance of practical, thoughtful support was in 1999 when I was told by my social worker, David Lloyd, how to disclose my HIV status. I mentioned the counselling given to me in the immediate aftermath of my suicide attempt, but after that initial consultation it was intermittent. Talking it out made me doubt myself and I even wondered if I was simply making it all up. Overall, it was not a particularly helpful program for me.

Section 7. Financial Assistance

70. I have not received any financial assistance.

Section 8. Other Issues

71. In an effort to claim compensation from Infected Blood Support Scheme, I have been trying to track down my medical records. The whole process feels like I am always two steps behind. Unlike the English IBS, The Northern Ireland IBS requires Proof of blood transfusion which would be easy if they had not destroyed all the evidence.

72. When I tried to get details of my blood transfusion at the Royal Victoria Hospital, I was initially told over the phone that they had been destroyed years ago. But a few months earlier, they were able to bring my medical records up on the computer and listed all my previous addresses back to the 1970's. I find this very strange. Unless only certain parts were destroyed.

Statement of Truth

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

Signed GRO-B

Dated 18/1/2020