ANONYMOUS

Witness Name: GRO-B
Statement No: WITN1399001
Exhibits: 0
Dated: January 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 My date of birth is GRO-B and I am GRO-B years old. I live at GRO-B with my wife and two children. GRO-B

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

Section 2. How infected

3. At the age of two I fell and cut my tongue which bled for hours. My parents rushed me to GRO-B Hospital where I had a number of tests and I was diagnosed with severe Haemophilia A.

4. I was treated with Cryoprecipitate at GRO-B Hospital. Shortly after this I was transferred to St. Helier Hospital in Carshalton and I continued to receive Cryoprecipitate here until the age of 12.

5. I was transferred to St. George's Hospital in Tooting, under the care of Professor Flute. When I was around 13/14 years old, my treatment was changed from Cryoprecipitate to the '*wonder drug*' Factor VIII. My parents were told that the reason for the change of treatment was so that I could self-treat at home and only attend the hospital for routine check-ups. My parents were not informed of any risks or side effects associated with Factor VIII.

6. I was initially treated with Factor VIII at the hospital before my father was shown how to administrate the treatment at home.

7. Growing up with Haemophilia affected my school life. I was always called '*the boy with the funny blood*'. I tried joining in as much as possible; however, I could never play some contact sports that I otherwise would have. I remember one instance when I had a swollen ankle and could not move, my physical education teacher called me lazy. When he was informed that I was haemophilic, he did not know what this was or what it meant.

8. I attended three different secondary schools during my education due to my Haemophilia and bullying.

9. When I was 16 years old I suffered a leg injury and I was examined by Dr Savage at St Thomas Hospital. He told me it was best to stay under his care if I wanted to walk again. I was admitted in to the hospital for six weeks and I received Factor VIII every day and night.

10. Sometime in or around 1984, I recall receiving a letter stating that I had to go to the hospital to see Dr Savage. During my appointment, I was informed that I had been infected with HIV as a direct result of the Factor VIII treatment. I was told that if I am lucky, I will probably have another two years to live. Dr Savage said I should '*go away and live my life*'. He told me that it is best if I kept this to myself due to the stigma attached to HIV and it being known as '*the gay plague*'. Dr Savage was unable to give me any further information at this point; I remember leaving the hospital very confused.

11. Sometime in or around 1985, I visited my GP, GRO-B due to feeling unwell and having pains in my stomach. I was already seeing him weekly at this stage for treatment of renal colic. I informed him that I was very unwell and I was experiencing intense stomach pains and loss of vision. He advised that I should go to the hospital immediately.

12. I went to see Dr Savage who carried out some tests, including blood tests. A few days later Dr Savage bluntly informed me that I have Hepatitis B. His exact words were, '*you have Hepatitis B, you have picked up a bit of shit in the blood'*. I was given some painkillers and advised that the infection should clear itself within a few months.

13. In 1991, 4 weeks after my first son was born, I was told by Dr Chisholm that I had been infected with the Hepatitis C Virus (HCV), which was a new kind of infection.

14. I was not given a lot of information on HCV, nor was I offered any treatment. Dr Chisholm referred me to Professor GRO-B, a liver specialist. He took some scans of my liver and after looking at them he told me that he did not need to see me anymore. Nothing further was discussed and I was discharged from his care.

Section 3. Other Infections

15. In 2006 I attended an appointment with Dr GRO-B who is now in charge of my care at GRO-B Hospital. I explained that I was feeling very breathless and fatigued. He examined me and I was immediately admitted in to hospital as I had developed pneumocystis pneumonia.

16. I have also developed Crohn's disease and arthritis and I was told that this is a long term side effect of having HIV and HCV.

Section 4. Consent

17. Every time I went for routine check-ups at the hospital, I always had a lot of blood taken and I was told it was '*for inhibitors*'.

18. I was never advised that I was being tested for either HIV or Hepatitis C. I was therefore tested, probably numerous times, without my knowledge or consent.

Section 5. Impact of the Infection

19. After Dr Savage told me I had been infected with HIV in 1984, I was flooded with emotion. I was a GRO-B at the time and I remember leaving the hospital feeling like I wanted to die. I struggled to contain my emotions so I started driving recklessly. I was swerving around cars in the opposite direction, I was driving extremely fast, I was so angry at what I had been told. I eventually pulled up outside the Old Bailey and just sat in the van for hours, trying to gather my thoughts and come to terms with the life changing news that I had just received. All my goals had been shattered and I felt like my life was falling apart.

20. That evening I told my parents about my HIV infection. They were devastated and simply could not believe it.

21. A friend of mine had a sister who was a nurse and she told him that everyone with Haemophilia had HIV, although I kept denying it, I was constantly accused of being infected. It was very difficult for me to have to listen to this every time it was bought up, and constantly denying it was mentally draining. This put a lot of strain on my relationship with my friends and I ended up distancing myself from them.

22. I just wanted someone to talk to and confide in but counselling was never offered to me. I was wary of telling people due to the stigma attached, but I desperately wanted to let it all out. I decided to speak to a former colleague

who also had Haemophilia and was treated with Factor VIII. I told him that I was infected with HIV but he immediately became defensive and said that he was not. He was adamant that he did not have HIV and indicated that the fact he had two children was proof of this. The conversation was very abrupt.

23. Due to the stigma surrounding HIV and the HCV, I decided to move from London and settle in GRO-B I struggled to form a serious relationship with any of my previous partners. When I eventually met my wife, I had to hide the fact that I was a Haemophilic infected with HIV and Hepatitis C. However, just before we got engaged I told her the truth. This was extremely difficult for her to hear, she broke down crying and was totally devastated, but she decided to stick by me which meant a lot to me. She was very supportive and I do not know what I would have done without her.

24. We went to see Dr Chisholm when we decided we wanted to start a family. I was told my wife should take her temperature everyday and monitor it so we knew when she was ovulating. We should then try once at that point. However, Dr Chisholm informed me that there was a chance that I could transfer HIV to my wife and I was always extremely worried about this. Luckily, my wife has not been infected; however she only got tested after we had our first child and so it was an extremely nervous period for us.

25. After my wife gave birth to our first child, she was treated very badly by the hospital staff. Although she was not infected, she was put in isolation so that she was not around the other mothers. I felt like this was all my fault and I could not do anything. I felt awful so I can only imagine how bad she felt.

26. We decided we would not tell our children about my infections. We wanted them to have a normal life. I had a friend who told his child about his own infection and this affected his child's studies and had a negative impact on his relationship with his friends. We didn't want to risk the same fate for our own children so we kept it a secret from them.

27. Even now that my children are fully grown up, they still do not know about my infections. I am too worried that telling them might rock the boat. My eldest son is trying to start a family with his wife; however I am deeply concerned that I will not see any of my potential grandchildren due to my infections.

28. I was forced to retire from my job at the age of 40 due to my ill health. In 2002 I was suffering form very bad bowel movements, and I was going to the toilet around 20 times a day. I was told that I had worn away the lining of my gland and had a perianal abscess. I had two drains placed, I had to physically push my left buttock to release faeces. I required dressings every time I went to the toilet. This was extremely humiliating, not to mention painful and difficult.

29. I was only given medication for my HIV in 2006. I cannot recall the name of the medication, but I do remember experiencing awful side effects. I had constant flu like symptoms and my mood was so up and down all the time. This was an extremely difficult time for me and my family as the side effects put a lot of strain on my relationship with them.

30. I was infected with HIV and the HCV by no fault of my own, and I was still made to chase for compensation. It was embarrassing and mentally draining having to beg for money that I was entitled to. I was a hard working man that was forced to retire due to my infection. If it wasn't for me being infected, I would still be working.

31. My financial circumstances were always difficult after I was infected with HIV and the HCV. At one point I had to lie about my infection in order to get my mortgage for my house, causing me a lot of stress.

Treatment/care/support

32. I was never offered counselling, but I feel this would have been greatly beneficial to me at the time. I just wanted someone to talk to, but I was always told to keep everything regarding my infections to myself.

33. I have never received any treatment for my Hepatitis C infection; **NOT RELEVANT** **NOT RELEVANT**.

34. I struggled to get basic dental treatment after my infection. My dentist who had treated everyone in the family for years did not want anything to do with me. I had to have four teeth taken out at St. Thomas' Hospital and was put into strict isolation with humiliating signs on the door warning people that I had a contagious disease. Even to this day I struggle to get treatment from dentists.

Financial Assistance

35. In 1991 I was involved in the HIV litigation. I received £20,000 from the McFarlane Trust. I have since received a further £40,000 from the McFarlane trust, and my wife received £2,000. I was told that I had to sign a waiver agreeing not to take any further action otherwise I would not receive this payment, nor would anyone else. I therefore signed as I felt I had no choice.

36. Since I was not told about the HCV until recently, I was not aware that I qualified for the Skipton Fund payment. When I did apply, I handed my form to Professor Savage who told me '*not to worry, I'll take care of it, you'll get your £20,000'*. My wife was there and she was extremely emotional. Skipton Fund contacted me and advised me that I did not qualify for any compensation as I was now clear from the HCV and my records were not clear as to when exactly. I have appealed this decision three times and I am still continuing to appeal.

37. I also receive £1,500 a month from the England Infected Blood Support Scheme.

Other Issues

38. I want to stress how destructive this has been on everyone directly involved, but also our families. I have been living a lie, and I still am. I am still scared of the consequences of people knowing about my HIV and I still feel trapped at all times.

39. No one thought of the long term implications of what they were doing when treating hemophiliacs with the Factor VIII. I want lessons to be learned from this.

40. I want an acknowledgement and an apology at the very least. My life was ripped away from me so I need to know that my wife and my family will be looked after when I am gone. People need be aware of what happened to us.

Anonymity, disclosure and redaction

1. I confirm that I wish to apply for anonymity and do not want to provide oral evidence to the Inquiry.

2. I understand a redacted statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed. GRO-C ....

Dated. 27.2.2019..........................