Witness Name: GRO-B
Statement No: WITN2912001
Exhibits: 0
Dated: April 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 GRO-B GRO-B. I live with my GRO-B GRO-B and I work in a GRO-B

2. I am an affected person in relation to my late partner GRO-B: P who received contaminated blood products. We met at Lord Mayor Treloar College and we were together until his death.

3. **This witness statement has been prepared without the benefit of access to my late partner's full 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

4. P had Haemophilia type classed as severe however his condition became worse towards the end of his life. P suffered with difficulty walking as he

had a lot of knee and ankle bleeds which caused him to develop arthritis. GRO-B GRO-B also suffers from Haemophilia.

5. P received Factor VIII concentrate every time he suffered an internal bleed. P never knew when he was going to have a bleed and therefore he wasn't aware how often he would receive this treatment. Sometimes he would have treatment 3 times a week and at other times he wouldn't need it for a couple of weeks. I recall that he briefly took Factor VIII prophylactically but that didn't last long. P really hated needles and having the injections so often destroyed his veins.

6. P was never warned in regard to the potential risks of receiving Factor VIII until it was too late. Given that he was so young his parents should have been informed and warned of the potential risks but they were never told anything. There is no way his parents would have consented to P receiving Factor VIII concentrate if there was any possibility that he would receive contaminated blood.

7. P received the majority of his treatment at Lord Mayor Treloar College and he started at the school at the age of 9. The only treating Doctor at the College that I can remember was called Dr Wasseff. There were others but I cannot remember their names. P was also a patient at Southampton General Hospital and received home treatment.

8. P was infected with HIV, Hepatitis B (HBV) and Hepatitis C (HCV) as a result of receiving contaminated blood products. He was infected while at the school between GRO-B. Unfortunately, his GRO-B was also infected with contaminated blood products.

9. The way in which the students were told that they had been infected was appalling. As far as I can remember, the Haemophiliacs who had been infected were taken into the library and told that they had been infected with contaminated blood. They were told this information without any parents, guardians or counsellors. They were far too young to understand at the time

what they were being told. The children brought into the meeting were all in the lower school at the time and P was only aged 11. The eldest child could only have been 14. They were told mid-week on a school day and there was no thought or care in delivering such dreadful news. The Haemophiliacs in the school were told to stick together and not to go near anyone else. The College didn't really tell P or his family anything once he was diagnosed.

10. I remember when the children were told they were infected they came out of the meeting laughing. They told people they were going to die of AIDS. I specifically remember them saying *"you need to stay away from us or you will be infected"*. They clearly had no idea what it meant but they had all been told they only had a couple of years to live. It was absolutely atrocious to do this to children. The students at the school who weren't Haemophiliacs were told to stay away from the Haemophiliacs. We were told we would catch something if we went near them.

11. I believe the same evening the parents received a telephone call and were asked if they had a particular batch number of Factor VIII and then told to take it to their nearest hospital. As far as I can recall this was the only information they received and they were not asked to come into the school or sent a letter detailing what had happened. Just a brief call and that was it.

12. The College must have known children had been infected sometime before. His parents were not told why they had to dispose of the blood however it does show that the College were aware that the blood had been contaminated.

13. I believe the only treatment that was available at the time was AZT. P was not offered any treatment and was just told that he would die. It was not until much later when he was in his early 30's that he was given medication. We are not sure of the precise dates when P was infected but given that he was 11 when he found out, it is possible that he went a number of years without treatment.

14. P developed Encephalopathy towards the end of his life and as a result it caused inflammation of his brain. As a consequence of the inflammation, P became very violent. He didn't hit me but I was threatened every day. I didn't know at the time why he had changed so much and I just thought the years of pain and anger had possibly turned him into a nasty person. I was later informed by a doctor that P drastic personality changes were a result of the infection affecting his brain.

15. P died of a head bleed on GRO-B in GRO-B at 33 years old. I was left alone with our 3 year old son. The cause of death on the death certificate was listed as encephalopathy. This is a recognised condition that can be caused by HCV, HBC and HIV. The death certificate also refers to his Hepatitis and HIV/AIDS infections as a cause of his death.

16. I had tried to obtain P medical notes about 2 weeks later but I was told that they had been destroyed.

Section 3. Other Infections

17. P was also told along with his GRO-B that they could have been infected with CJD through contaminated blood.

Section 4. Consent

18. P must have been tested without his knowledge because everyone was shocked when they were told about the infected blood. There had never been any indication that tests had taken place or that there had been a concern of any possible contamination.

19. Having had time over the last few years to think about it, it sounds to me like they experimented and conducted research on the Haemophiliacs. It looks like they used Haemophiliacs as guinea pigs. I watched the documentary on Panorama with GRO-B and I was horrified. I couldn't believe that

they took blood from Russian corpses and gave it to people that needed blood.

Section 5. Impact of the Infection

20. I attended the same school as P and we started off as friends for the first couple of years. I was madly in love with him and after some time we started a relationship. We were so close and we stayed together until his death. I lived with his family in GRO-B for about 3 years before we moved to GRO-B

21. We both wanted children but P said no because of the risks associated with his infection and it could affect me and our children. We went to see a geneticist at St Thomas Hospital and he told us that we could try for a child using the sperm washing method but advised us to attempt natural conception 3 times. We risked intercourse once and I got pregnant immediately. Things were great throughout our entire relationship until the last 6 months of P life. We were engaged when P died.

22. P became extremely angry because of his infection and his life had been shortened through no fault of his own. He put on a lot of weight and was extremely overweight at one point. He had been told he would know when he was dying because he would start to lose a lot of weight and he then ate as much as he could. He was in denial about everything.

23. P would shut down emotionally quite often. It was his way of dealing with things. His family would usually sit at the dinner table and discuss things, they were very open. If infections were ever brought up P wouldn't talk about it at all unlike his older brother who was a lot more open. P would not talk about his feelings and he kept a lot to himself which must have been very difficult. P had a very close relationship with his father and brother and I know he spoke to his brother about the treatments they received. However, his father told me if he tried to discuss anything in regards to the infections he would just be shut down by P.

24. I really feel that P was ashamed that he had been infected with HIV. At that time it had been all over the news combined with lots of scaremongering. People believed that all you had to do was touch someone and you could be infected with HIV. We knew that this wasn't true but the general public did not and therefore it wasn't something you would share with anyone. P was also very homophobic and I had a few friends who were gay but I could not mention them as it made him very angry. He had convinced himself that HIV was for gay people and drug addicts and therefore he would be okay. It was all quite bizarre.

25. In 2004, a year or so before P became really poorly he was given treatment for Hepatitis C. It was absolutely horrific and it caused him terrible bruises that were the size of dinner plates. The treatment made the whole side of his body turn black from bruises. He was told by a consultant that the treatment caused living organisms to start growing inside of him and it absolutely petrified P

26. I recall at one time the treatment required him to take 30 tablets a day. He was told he would need to take the treatment for an initial 6 months and if it worked he would require an additional 6 months of treatment. The treatment seemed like it was effective but he was taken off it because he was very unwell as a result of complications to do with his other infections. When he was taken off the treatment he still had the HCV virus but it was undetectable. It was so frustrating because it proved the treatment worked and if he had received it earlier it could have prolonged his life.

27. When P was on the medication for Hepatitis C he became very angry and aggressive. I understand it was a recognised side effect of the treatment and it presented with similar symptoms to Premenstrual Syndrome (PMT). At first the episodes only occurred 2 or 3 days in a month. However, towards the end of his life they occurred all the time and it was only 2 or 3 days that he wasn't aggressive. His family were aware that this was going on but didn't know how to help. I had to deal with it on my own and in the end I just pretended everything was fine.

28. P regularly went to Epsom Hospital and latterly he went to St Thomas' Hospital. On the days that he went to hospital life stopped for that day and then we would return to normality until the next time.

29. Our son was born at the end of GRO-B and P stopped me attending any hospital appointments with him. Prior to his birth, I had always attended. I thought that everything seemed as normal as it could be in regards to his health. However, P brother thought it was around that time P may have been informed that his illness was terminal and he didn't have much longer to live, which is why he didn't want me there. He wouldn't tell me anything about the appointments. It was stressful not knowing what was going on.

30. In 2004 when P was still receiving treatment he wouldn't be able to sleep. The treatment was very harsh and I don't think he really wanted to persist due to all the issues it caused, however he wanted to stay alive and see his son grow up.

31. The Encephalopathy made P incredibly aggressive and cruel in the last 6 months of his life. I lived in fear of being beaten every day. I was also verbally, emotionally and sexually abused during this period.

32. With everything that was going on I became a shadow of myself. My whole life changed so much and so quickly. Everyone noticed I had changed and could see that I was constantly petrified but I tried to put on an act in front of everyone. Although P wouldn't be aggressive in front of others they could tell what was going on and that I was masking how I felt. His infection which led to his Encephalopathy meant I never felt safe and had to worry about everything. His anger got worse and worse and he was physically and verbally abusive towards me.

33. As time went on P wasn't just aggressive to me but also towards our son. There was an occasion where he threatened GRO-B with a piece of wood and I had to stand in-between them to protect my son. I called P dad and told him what had happened and he told me to call the police.

34. The only option I was offered when I called the police was temporary accommodation at a shelter. They told me I could only bring one set of clothes and one toy for my son. For me because of my own disability of Spina Bifida, that was not feasible, in addition they told me that I wasn't allowed to bring my dog to the shelter. P also used to be very violent with my dog and he would beat it because he knew it would hurt me. P also threatened to break my dog's neck if I left him and that he would be able to get custody of our son. I needed to keep my son and dog safe and that's why I stayed.

35. All these actions were completely out of P character. He had never been like that before and I have no doubt that his change in behaviour was due to complications from his infections from contaminated blood. He had always been such a lovely and nice man. We had been together for most of our lives and I knew it wasn't him however it was so hard to be treated that way and to fear for the safety of my family.

36. He had sudden changes in behaviour that made me question his sanity. I remember we went for a meal on the GRO-B 4 days before he passed away. Things were very horrible and I only went for the meal so I wouldn't be treated any worse. I remember he sat and told my son how lovely I was and what a good mum I was. Just earlier that day he had threatened me and I remember thinking at the time he had gone mad.

37. On GRO-B P woke up and had issues walking. He stumbled around, struggled to walk or use his hands and became very angry with himself, it was very sad to see. After he had a bath he went back to bed which was very out of character because we had family coming over. He had difficulty speaking and couldn't walk. I called his brother who immediately thought it was a head bleed. I called for an ambulance despite the fact P had said earlier he didn't want one.

38 P had deteriorated so badly by the time the ambulance arrived that he couldn't move and the paramedics had to carry him down the stairs. My step-

father went with him in the ambulance because I had to look after my son and I wanted to give him some normality.

39. I went to the hospital later that evening and P was in and out of consciousness. He told me to go home so our son could open his presents. I believe that was a sign that he knew how bad things were and he wouldn't be coming home. I had no idea and I thought everything would be okay and that he would be home in a few days.

40. The hospital told me to call back at midnight because they wanted to carry out a CAT scan and I tried to call but couldn't get through to anyone. The hospital called me just after midnight and were very blunt. They told me I needed to come down and turn off his life support machine. I was in complete shock. I had to call his family and tell them they had to get to the hospital as soon as possible. They lived in GRO-B ; a good hour and a half away. By the time I got to the hospital his life support machine had been turned off because his organs had failed. When his mother arrived she was told in the corridor and she let out a horrific blood-curdling scream. He died at around 1.15am.

41. I was never told how serious P condition had become. I had a call from the doctor between Christmas and New Year who told me P would have been in an enormous amount of pain around the time of his death. His brain had swelled to the point it was going to burst. I had this conversation because I needed to understand what had happened.

42. When P died I no longer had someone who would look after and care for me. The emotional effect on me is impossible to quantify. I lost my best friend, my carer, partner and my son's dad. Some days I will hear a song and it will make me cry. P has been gone 13 years and it still affects me every single day.

43. I am 47 years old and I will be alone for the foreseeable future. My son is GRO-C and at some point he will go off into the world and I am very conscious of that.

44. However, because of the way that P treated me towards the end of his life I find it very hard to trust people. I know it wasn't him but I feel like I have to protect myself. The P that I like to remember was the man before his infection started to affect him, when he was happy and we would always be doing something nice. When he became ill he changed so much and he didn't even look the same.

45. My son has had to grow up without a father because of the contaminated blood P received. This is horrendous for any child. We had friends who would help out and include him on family trips with their kids but at the end of the day he didn't have a father which was awful for him and he just had to accept it. He has a few memories of P which I am glad about but he never got to know his father which is very hard for him.

46. My son attended counselling sessions from the age of 6 through the Child and GRO-B because he struggled so much. I was told he would need counselling every few years.

47. When GRO-B was 11 he went to the local high school for boys, he was determined to go but he only lasted 18 months there. He suffered such severe anxiety and depression that he was forced to stop attending school in year 8. He hasn't been to school in over 2 years and is now studying through an online school in order to complete his GCSE's. He is only able to study English, Maths and Science because he has missed so much school.

48. GRO-B wants to do an apprenticeship and he is going to enrol into a college in GRO-B which he will attend once a week which will be good for him. He will also be able to spend time with his family there. He's a very bright and practical boy.

49. GRO-B is very anxious especially around men and he really has had a very tough life. He has been prescribed fluoxetine which he takes daily and if he doesn't take the medication he is unable to leave his room due to his mental health issues.

50. My son has been bullied quite a lot and he will check social media before he goes out to make sure that people who will give him a hard time won't be somewhere he is going. I believe all of these issues stem from his father dying when he was so young.

51. Due to all the difficulties my son has already had to face as a result of losing his father I have never been able to tell him certain details about his father. He doesn't know that his father passed away on GRO-B or that he was abusive towards me. I don't want to make his mental health worse but I don't like having to keep things from him, however I feel I must in order to protect him.

52. P family has had it very hard. His parents had two sons' that suffered with Haemophilia and both were infected with contaminated blood. P mother suffered a huge amount of mental health issues as a result. She blamed herself for what happened and we had to constantly reassure her that it wasn't her fault.

53. P father was very angry about what happened and how everything was dealt with by medical professionals. The fact that they weren't prepared or counselled when given the news of his son's infections angered him greatly. His parents were never told why they had to throw away the 'bad blood' that they had been given and they were never invited in to the College and spoken to in person. P father passed away 6 weeks after P died. He died of cancer and as P was his favourite, I believe he gave up.

54. P worked at GRO-B bank in GRO-B when he was around 19 years old. He worked hard but wasn't able to go in sometimes because he would be in such awful pain. When we moved to GRO-B he got a job with a charity and he would drive people who were visually impaired. He managed to do this job for about 18 months until it became too difficult for him. He hated letting people down but when he was in too much pain he just couldn't work. His pain was so severe that on most days he would have to take painkillers just to be able to leave bed. The job made him very happy but unfortunately he had to give it up and he stopped working in or about 2001.

55. After P stopped working, I got pregnant and P continued to be my carer. I had had to stop work at the age of 21 because I had pressure sores and neither of us were able to work. When my son started school, I worked as a helper at his school. I then started work as a volunteer Teaching Assistant in 2007, the week after my son had started reception. I became employed as a paid teaching assistant when GRO-B started in year 4. My doctor signed me back to work and it helped keep me busy after P passed away.

56. Financially we struggle now because there's only me and GRO-B. I can only work part time at the school so we don't have much money coming in. Due to the changes with EIBSS I no longer receive any financial assistance and I have been told that I don't meet the threshold. I find this totally bizarre considering the circumstances and I try not to think about it. However, without a doubt financially it's been very hard.

57. I haven't been able to give my son the things he would have had if his father had been alive. We stopped receiving the money that P was getting when he died. I feel like there is no protection for us and I have to make all the decisions. When my son was growing up I had to raise him as a single parent and I had no one to discuss what was in my son's best interests.

Section 6. Treatment/care/support

58. I do not believe P was offered any treatment or support after finding out about his infection.

59. I was never offered any treatment, care or support in relation to P infection.

60. I was never offered psychological help or bereavement counselling.

Section 7. Financial Assistance

61. P was party to the HIV litigation that ended in 1991 and received around £20,000. I believe he signed the waiver agreeing not to take further action under duress.

62. In 2003, the Macfarlane trust told P that he should apply for a compensation payment for his Hepatitis C. He was told the compensation would have amounted to around £32,000. However, when he applied they refused his claim even though his doctor filled out the form for him and said he was entitled to it. He was denied the money because he was told his Hepatitis wasn't bad enough. At the time, we really needed the money as we wanted to buy somewhere to live so we would have some security while dealing with the terrible ordeal. The two previous houses we were renting were sold meaning we had to leave. My son and I have been in the house we are currently renting for 13 years but the owner is very elderly. We can never feel a state of security or stability because we feel like we might have to leave. There is no way I would ever be able to earn enough money to qualify for a mortgage.

63. P was not party to any other litigation.

64. After P passed away the Macfarlane Trust gave me £2,500 towards his funeral. And I think I also managed to secure a social fund loan to help me with the funeral because it came to £4,000.

65. I received £10,000 last year in relation to P death. This was provided for widows through the Skipton Fund.

66. Last year when I was undergoing my teacher training course I received a grant of £1,500 in order to help pay the £7,500 fee.

67. I have been told by the Macfarlane Trust that P received £369 per month and I received this for around 6 months after his death. I was told it would

drop to £300 but they changed it to £250 per month and I was not sure why. Six months ago before my son turned 16 the monthly payments stopped. I tried to speak to my local MP about it but it didn't do any good. I received several small sums that equated to just over £2,000 and then the money was stopped.

68. I did not receive any other financial assistance and when P passed away any benefits we received stopped because they were all in his name. The benefits office lost all details with my information and therefore there was a period of time when no money was coming in at all. This was a really difficult time as I had to borrow money from my brother in order to pay my bills. We received a lump sum for the back pay we were owed.

Section 8. Other Issues

69. It's an absolute disgrace that it has taken this long to get any answers. So many people are not going to be around to see an outcome because it has taken so long. These people have had their lives cut short and lived in constant fear of dying. They have been treated appallingly.

70. People should not have been given contaminated blood in the first place but the fact medical staff were so blasé about it all makes it worse. People should have also been offered appropriate help and counselling.

71. I want to know why all of P notes were destroyed. He died on GRO-B GRO-B and two weeks later his notes had been destroyed. The fact that they managed to do this at such a busy period time of the year and in such a short period of time shows to me they were actively trying to cover up this entire ordeal. I want to know why.

72. As far as I am concerned they knew exactly what they were doing and didn't care. They assumed all those infected would die shortly after receiving

contaminated blood and they wouldn't have to deal with any of the repercussions.

Anonymity

73. I wish to remain anonymous.

74. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-B ....

GRO-B

Dated..10.5.2019................