Witness Name GRO-B
Statement No: WITN3521001
Exhibits: 0
Dated: September 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 live at GRO-B GRO-B I live with my mother and I am currently working as an GRO-B I worked for GRO-B for three years, before moving on to work in a college.

2. I make this statement in relation to my late GRO-B: F. He was born on GRO-B GRO-B and passed away on GRO-B having contracted Hepatitis C and HIV, as a result of receiving contaminated blood products.

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

Section 2. How infected

4. F was diagnosed with Haemophilia A from birth; although I do not how severe it was deemed to be. F older brother also suffered from Haemophilia, so the hospital was very much aware of the condition. F Haemophilia was very noticeable. He would regularly get injuries in his ankles and joints and these would cause very painful swelling

and internal bleeds. Because of the painful joints and bleeds his mobility was poor and he heavily relied on his car to get around. He also suffered from a lot of nose bleeds.

5. In order to treat his Haemophilia, F received human Factor VIII concentrate and tranexamic acid when the bleeds got really bad and would not stop on their own.

6. As far as I am aware F was registered with GRO-B and Kings College Hospital (KCH). I am not sure where he was infected but he was seen at both hospitals. Towards the end of his life, most of his treatment was carried out at KCH where he attended the renal and virology clinics and was an inpatient for his ill health and transplantation.

7. I do not know which blood products F was given in infancy, but know he received human Factor VIII concentrate and relied on taking it at least once a week. His mother took care of his health during his childhood.

8. In order to obtain Factor VIII treatment, the hospital required F to complete forms to show exactly where he had been injured and to locate the bleed or swelling. If he failed to complete these forms, they refused to deliver his treatment (which was disgusting as Factor VIII was vital for F survival).

9. I do not believe F or his mother were informed about the risk of infection from using Factor VIII concentrates. She was informed that her children needed the treatment or else they would die.

10 F was infected with HIV and Hepatitis C as a result of receiving contaminated blood products.

11 F was diagnosed with HIV at around the age of GRO-B. I do not know how or when F was informed about this. I cannot say whether he had been feeling unwell and went to the hospital, or if it was the hospital who initiated a consultation, upon becoming aware of the risks of infection carried in the blood products. For this reason I cannot explain what information or advice, if any, was provided to F or his parents about his HIV infection.

12 F was informed that he was Hepatitis C positive when he was around the age of GRO-B GRO-B. Prior to this, he had undergone blood tests to check for other infections. His grandmother accompanied him for this test and was devastated to find out that he had also contracted Hepatitis C. He was already suffering with Haemophilia and HIV and then

suddenly also had to deal with Hepatitis C. At that consultation, I believe F was told that he would need a liver transplant by the age of around GRO-B

13. I later asked F grandmother about the consultation and her views were that it was very matter of fact and no information was given to help F manage or understand his Hepatitis C.

14. In terms of the risk of others being infected as a result of the infection, I was never advised by any of the doctors at the hospitals on how to protect myself. I researched the matter myself using the internet and followed guidance from F

Section 3. Other Infections

15. F had to receive a liver transplant. This was carried out at the KCH after which he was barrier nursed and kept in isolation. The isolation notice on the door advised that there was a risk of vCJD, but the hospital would not give us any information as to why he was quarantined in this way or if he did in fact have vCJD.

16. This was a huge concern of mine. Signs were placed on doors claiming that he had to be quarantined. The hospital said it was just a precaution, but they were going as far as putting signs up so I asked for advice on the matter. If he did have vCJD, it was a risk to our whole family. Despite my request, no advice was ever given to me.

17. For the first few weeks after the transplant (in quarantine) he was okay, but then he started to feel very unwell. The hospital took a biopsy of the liver, but advised me that they could not test it in the hospital laboratory. They informed us they were sending his tissue sample to a temporary lab which would later be burnt down. This would take over six weeks to arrange. By this point I had assumed that the specimen would have become spoilt. No explanation was given as to why he was treated so differently. They wouldn't give me any information on where this temporary laboratory was or why it was taking so long to coordinate this biopsy either.

18. I am not sure if F consented to this test. We were both physically and emotionally exhausted by this point, running on adrenalin through lack of sleep and worry.

19. When we received the results, we were advised the Hepatitis C had returned. The doctors had advised that he had a rare form of Hepatitis C and it was causing fibroids to grow in the liver. We were advised that he would require another liver transplant to survive.

20. Prior to the barrier nursing, neither F nor I even thought of the possibility of vCJD and had never been advised this was a risk, so if he had any other infections, I wouldn't have considered it. Any symptoms he showed I attributed to Hepatitis C and HIV.

Section 4. Consent

21. If F mother had known about the risk of infection carried through Factor VIII concentrate products, she would have thought twice before consenting to her children's haemophilia treatment. Instead her understanding was that if her children did not have Factor VIII concentrate, they would die. Nothing further than that was ever discussed with her and there was no mention of the possibility of them being at risk of anything.

22. I do not know if F parents consented to his HIV test. He was only GRO-B years old when diagnosed, so I do not know much regarding the matter.

23 F was aware that he was being tested for other infections when he was tested for Hepatitis C.

24. I do believe that F was tested for the purposes of research during his trial of the Interferon treatment. GRO-B at KCH took blood samples from F every week to assist him with his research paper. I do not know if F consented to this; I assume he did. The hospital were taking so much blood from him before the transplant that he asked GRO-B to stop these blood samples.

Section 5. Impact of the Infection

25 F suffered from terrible depression. He had very low self esteem and was constantly fearful and anxious. In his short GRO-B years, he suffered daily from the effects of his haemophilia, low immune system and from the liver disease.

26. We attended weekly appointments at the renal department waiting hours to be seen by his consultants GRO-B to ride the rollercoaster of ups and downs. It was

mostly downs and we would come away from there feeling hopeless. F would be feeling unwell and the appointments, waiting time and blood tests would leave him exhausted.

27. In terms of the actual effects of Hepatitis C, when we first started our relationship, F would occasionally get confused and wouldn't quite understand what you were saying. His reply to my comments would be unrelated and random. I didn't realise that the effects on the liver could cause brain fog. F wasn't able to think clearly when this happened at all. Once we were holidaying in Spain and he kept thinking we were in Turkey and speaking GRO-B to the locals. His command of GRO-B was limited, but he knew a few words. F had a very weak immune system that made him more susceptible to colds and he would get cold sores around his mouth.

28. In addition to low self esteem, F suffered from mood swings often losing his temper very quickly without sound reason. For the most part F kept his emotions to himself. He wouldn't tell me that he was feeling low and instead would become angry and introvert. I would wait for him to calm down before talking to him about why he was angry and upset and try and help him through it. F also suffered from paranoia, which had adverse effects on his moods and how he saw things.

29. The health complications he had in relation to his liver included; gallstones, asities (pain caused by the weight of swelling in his body,) jaundice, dark frothy urine, fatigue, paranoia, mood swings, brain fog, confusion and insomnia, lack of appetite, diarrhoea, indigestion, brain haemorrhage and potential vCJD (never confirmed).

30. As mentioned above, he also had a low immune system which made him susceptible to colds and flus, cold sores, shingles, psoriasis (the itching drove him mad), migraines and tension headaches and other infections causing high temperatures, rigor and cold sweats. Meanwhile, he still had to deal with Haemophilia related issues like joint bleeds, pains and swelling.

31. Before I lived with him F did not visit his consultants often. From GRO-B I started attending his appointments with him every week. F would try and shield everyone from his illness and problems so they would not get upset, but I was always by his side looking after him and taking on board the information the consultants gave us at weekly appointments.

32. For his Hepatitis C, F started a course of Interferon at KCH and was under the care of GRO-B. He had to have one injection on a weekly basis. F trialled Interferon twice when it was in the testing phase but both treatments were unsuccessful. The second course commenced prior to GRO-B but was stopped within six months, as it was not helping and worsened his health instead. It was during this course of treatment that GRO-B started taking blood from F for a research paper he was preparing.

33. After GRO-B F was put on the transplant list. The hospital tried to explain the process to F but he just was not able to absorb the information. I had to repeat and simplify what was being said.

34. Between GRO-B, we were called into the hospital eight times on the premise that the transplant was ready to go ahead. Each time we would be in the waiting room between 16-24 hours, before being given an excuse as to why the transplant could not go ahead. F was repeatedly sent home with no progress. On the first time he was called in, the liver they had for him had been infected previously with Hepatitis B, but he was too unwell to undergo surgery that day.

35. In GRO-B F finally received his first liver transplant and spent four weeks recovering in hospital. He was sent home on my birthday and we were under the impression that the transplant went well, that the liver was a good fit and the surgeon had done a fantastic job.

36. At first he seemed well, although he was a bit sore from the scarring. He was slightly restless as he had been staying in a hospital bed for ages and it had been an extremely traumatic procedure. He looked very pale due to major blood loss (for some reason, the doctors chose not to give him a transfusion during the operation) but he seemed to be recovering.

37. Unfortunately, the scar from his operation never healed properly and he became very worried about it. The doctors always told him not to worry and that it was just healing slowly. The majority of the scar had healed but part of the wound was not healing, it was still raw and wept blood and puss. We cleaned it with alcohol swabs to try and stop infection.

38. It was later discovered that F had an infection that the hospital could not locate.

39. The bloating started to come back. Fluid built up in F stomach and his GRO-B swelled up to the extent that his GRO-B hid inside. This was extremely painful and hindered his mobility. He felt extremely uncomfortable and was unable to eat. Whenever he consumed food, it was not digesting and passed in its form. His liver was deteriorating completely F became so very run down and skinny and looked like he was a victim from a concentration camp. His bones stuck out and when he had a bath the water would hurt his skin.

40. The hospital said they could offer F a second liver transplant but I felt like they knew he wouldn't make it to that point. They had no intention of going through with the procedure.

41. It was discovered after his transplant, that F had a rare form of the Hepatitis C virus that only makes up 5% of cases. This was realised after the virus started to grow fibroids in his liver.

42. Towards the end of his life, F was constantly in and out of hospital for vitamin K drips and fluids. He contracted MRSA in hospital regularly and was discharged and sent him home, to recover from it. He had a virus that they could not locate and had to have antibiotics via a drip on a few occasions.

43. One of the registrars accused me of passing MRSA onto him and advised I would have to be tested. I explained this was not the case and he was usually sent home when the result was positive, to recover at home. He never had it when he went into hospital, but would contract whilst there. I told him it was fine to test me, at which point he backed off. I wanted them to test me, so I could prove it was the hospital infecting him and not me.

44. His consultant, GRO-B at KCH even agreed that he would always get much better at home after treatment in hospital. This is because I provided him with 24/7 care.

45. On the morning of F brain haemorrhage he was supposed to come home but at 8.30am I was called into hospital. They told me not to worry and that I would get to speak with F when I got there. I thought he may have had a stroke, but was not prepared for what had happened. When I arrived I found out that he had suffered a brain haemorrhage and he was brain dead, the hospital advised if he survived he would be a vegetable.

46. The hospital's care of F was extremely poor when it happened. I found out he had been left on the bathroom floor covered in blood for hours. If the two hourly temperature and blood pressure checks had been completed; they would have discovered him sooner.

They had advised that these had not been done during the night to allow him to rest. He was found at around 4.30am. I was told that even though he was not found straightaway, the bleeding was from the core of the brain and there would have been nothing they could do. I always wondered if that was true or if they just found him too late. That morning he was sent for a scan but the bleed was so severe, they advised they would have to drill into his scull to relieve the pressure and that would cause even more damage to his brain. The only thing they could do was put him on a life support machine.

47. In my heart I know they couldn't have saved F because he was so sick; he would have passed away eventually anyway. After F transplant and when the Hepatitis C came back, his consultant told him "you are in between a rock and a hard place." He had no chance of surviving. The infected Factor VIII he was given was a death sentence.

48. When F went onto life support, I was told once the machine was switched off he could survive for up to three days, but would be completely in a coma. The hospital advised if he did survive he would be a vegetable. When he was on life support he had a lot of family and friends visiting to say goodbye. I was in a total state of devastation, shock and heart break and I remember the staff coming in and trying to get me to give permission for the machine to be turned off. Not everyone had said goodbye and I wanted them to have the opportunity before they switched it off. I managed to hold them off until 8pm that night. All of his friends and family were there, along with my family too.

49. In his very last moment, it was just me and him. He was not aware of his surroundings at all, blood dripped from his nose and he was in a terrible mess. I told him it was ok to go to rest and I loved him very much and always would. After he passed, the nursing staff took all the apparatus away and I noticed just how his body was so very jaundiced and entirely yellow, even his gums and tongue.

50. F passed away at 9pm that night. I packed up his belongings with my mother and left the hospital in shock and completely broken. To this date, it was the worst experience of my life and probably will remain so. You never ever get over something like that. I still get flashes of his yellow lifeless body shrivelled up in that hospital bed and it kills me.

51. On F death certificate, his causes of death are listed as HIV, Hepatitis C, Haemophilia and Brain Haemorrhage.

52. F was never really a social person as he grew up with several health complications, which severely restricted him from engaging in activities. Mentally, he felt very bad about

himself and was constantly depressed. Very occasionally he would go out, but overall he just wasn't really interested F became a recluse and stayed at home a lot of the time. Whilst at home he would shut himself in with the curtains permanently drawn. His family would have to come and visit him most of the time.

53. F and I were together for nearly 10 years before he died. Our mothers were friends from the age of 5 and so we grew up together, along with his brother GRO-B: B. F told his mother that he liked me and I dropped the hint that we should start a relationship. I was 20 years old and he was 24 at the time. We were very close from a young age and so I was always aware of his health conditions from the outset. It was never hidden from me.

54. During our teenage years F and I drifted apart slightly but when I turned around 16 or 17 years old, we began to meet each other more often when my mother and I would visit his mother. He was very quiet and shy and kept things to himself. He held a lot in and didn't share very much. In the beginning stages of our relationship I noticed he was getting symptoms of the infections but nearer the end of his life it had become far worse. I accompanied him on his hospital appointments and listened to the advice of consultants to gain a better understand of the medications and treatments.

55. As I was F carer, I also sacrificed a lot of my social life. When I was a teenager, I would go out with my friends and to social events with my colleagues, but when F health declined, I had to stay at home with him. I assumed the role of his carer and ensured that his needs were catered to.

56. I provided 24 hour care for him and I had to do this alone, without any help from anyone. My mum would come over and stay on weekends so I could get some rest, but I was alone in the week. I would not sleep for days from worrying and the need to be on call, to get whatever F needed, whenever he needed it. I suffered from migraines, exhaustion and anxiety, but I had to fight through all of this to make sure he was cared for.

57. It was very difficult to keep my emotions under wraps while looking after someone and trying to keep them calm, when I was falling apart myself. I was only 28 years old and it was a massive undertaking. We lived on a very large hill and he would usually drive me to get groceries while he stayed in the car, but he was no longer able to do so. I had to assume the responsibility of shopping but anytime I left the house, I would constantly worry about F in case he fell over and hurt himself and I was not in the house to help him. For that reason I had to be as quick as possible. It was very stressful and this stress continued

throughout the day. At home, whilst I cooked dinner, I would worry if he would even be able to eat the food I was making. I kept F in an extremely clean environment after his surgery and always made sure the handrails and door handles were disinfected regularly.

58. F found it very hard to sleep because of the pain and discomfort he felt so I would talk to him and cuddle him in an attempt to make him as comfortable as possible. He would get very cold one minute and then would be burning up and want ice lollies the next. F was so poorly that he was even unable to have baths. In my heart I knew something was very wrong, but I never realised I was giving him end of life care.

59. A few days prior to F passing, I was so upset that I broke down while on the phone to my mother downstairs. I didn't want him to hear me, but he did and called me upstairs to see what was wrong. I told him about my worries and we both cried together that night. I chose not to see his body after his death as the undertakers advised me that they could not embalm him. They did not explain why. I can still vividly remember how he looked on the night he died and I couldn't go through that again.

60. I am a shell of the person I once was after this experience. This has totally ruined me. I have lost my best friend, soulmate and fiancé. I have lost the chance to have a family with him and spend the rest of my life with the one person I truly loved. I take antidepressants to get up in the morning and get me through the day. Without them, I am a depressed and anxious mess. I suffer from panic attacks and anxiety that causes heavy sweating, restless legs syndrome, obsessive compulsive disorder, paranoia, disrupted sleep, weight problems and comfort eating. At my heaviest, I was 15.5 stones. I have severe depression without the tablets and I do not want to leave the house. I just want to stay in bed with the curtains drawn. I have very low self-esteem and have struggled to cope with the emotional pain of my loss.

61. I tried to come off the antidepressants, but was not ready and very quickly became a mess again, so I had to go straight back on them. If I don't have them I can't get up and function. Witnessing the person I loved deteriorate in health to that extent, took a massive toll on me.

62. Four years ago, my bereavement councillor confirmed that I have post traumatic stress disorder (PTSD). I still see flashes of F dead body just after he died. He was completely yellow, even his tongue. That day was the hardest day of my life; I lost my best friend, the love of my life and my soul mate. We were inseparable and had something very few people manage to find in a lifetime. We were engaged to be married and were planning

to have a family if all went well. The hardest thing you can ever do is say goodbye to your loved one and tell them it is okay to go to rest because you know they will never wake up.

63. In terms of the stigma of HIV and Hepatitis C, F condition wasn't something shared openly by me. I kept it very much to myself and because it was never made public I never faced any stigma or discrimination.

64. On the other hand, throughout F life experiences, there were several times when he felt stigmatised. It was because of this that he lacked so much self confidence and spent a lot of time at home. He had these encounters from a very young age.

65. When F first enrolled into primary school, his parents disclosed F HIV positive status and the school refused to admit him. This happened with a few schools and from a young age, F was made to feel different and like he wasn't meant to fit into society.

66. Even after his death, F was subjected to stigma. I arranged and paid for the funeral and it was all done very quickly. I received the paperwork releasing his body, but the undertaker would not embalm him. He gave us no reasons and just simply said they couldn't.

67. The impact of losing F on his family was devastating. F was loved by so many people and as I mentioned, when he was on life support, so many people came to see him.

68. F had a brother named B and he was also infected with HIV and carried the Hepatitis C virus, although he was not affected by it. B contracted Hodgkin's disease and during the second bout of cancer, he died from sepsis because of his low immune system.

69. I do not have much clinical information on B, but I wanted to mention him, as he has been another victim of this tragedy. He suffered much the same as F with the pains, weak joints, low immunity and depression.

70. F mum was completely broken. She dedicated her life to raising her two boys, administering their medications as required and providing them with all the love, care and support she could to try and keep them as healthy and happy as she could. She suffered from clinical depression because of this tragedy and was heart broken with what had happened to her children. Sadly, she passed away in January 2011 from cancer, just prior to F death. B later passed away in GRO-B

71. F knew he couldn't work because of his physical weakness. He was sick as a youngster and missed a lot of time at school because of his condition. Having been discriminated against and severely stigmatised, he found it hard going to school and even harder when he was falling behind academically because of time off for his illness.

72. When I was GRO-B years old, I started my first job. I was in full time employment, but I left that role to take on the carer role. I had to claim benefits to survive and was put through interviews at the benefits office before my allowance was sorted. This put a great financial strain on us because I was not earning my salary. I could have achieved so much more in life, but could not take up any opportunities, because of the care F required. I would never have been able to leave him alone.

73. After F passed away, I moved back home with my mum and was unemployed for a while. I applied to GRO-B within the GRO-B department and was lucky enough to get the job. I have continued to work in GRO-B GRO-B and hope to continue to progress. I've worked extremely hard to get myself to where I am, but I still feel like I am not quite there yet. My current role is not what I was interested in, but was more something I became engrossed in as I was so desperate for money.

Section 6. Treatment/care/support

74. In terms of the difficulties F faced in receiving treatment, the main issues were with regards to his liver transplant. We were called in eight times before the transplant was actually performed.

75. Post transplant, F was prescribed tablets to stop his body from rejecting the liver. He also had to attend the hospital weekly to be monitored.

76. F was taking medication for his HIV, but I am unsure of the name of the medication. After his transplant he was taking a total of 26 tablets a day. We had to ensure his life was correctly timetabled and everything done as per a strict routine, as each medication had a different dosage requirement and some could not be taken with food.

77. I believe no counselling or psychological support was ever made available to F as a result of him being infected with HIV and Hepatitis C. This was definitely the case after we got together.

78. No counselling or psychological support was made available to me during this period. I was offered counselling eventually due to the need for bereavement support. Not long ago, I explained to my counsellor that I suffered from PTSD and that it completely destroyed me. I explained that I was in another relationship, but it's not the same. F was my first love and soulmate. It was and still is, very difficult to move on.

79. I did not find these sessions useful at all as my counsellor failed to address the issues I raised.

Section 7. Financial Assistance

80. When F was alive, he was given monthly payments from the MacFarlane Trust (MFT) although I do not recall the amount given.

81. In 1991, F was part of the US Litigation and received a payment of £22,000 in 2010. He also received the Stage 1 payment of £20,000 from the Skipton Fund.

82. After his death, for a period of 9 months to 1 year, The Macfarlane Trust (MFT) paid me around £1,100. I also received a bereaved widow's payment of £10,000 in November 2011.

83. When I first went to the MFT for assistance, I spoke with a representative who was not helpful whatsoever. It was difficult for me to find all the information she needed for my application and in the end I was unable to provide anything at all. I went a few months without receiving anything as I did not meet her criteria.

84. I tried to contact the MFT a second time and spoke with a different person who informed me that the first representative I had been liaising with, made things overly difficult for me and that the process was in fact much more straightforward. She sorted everything out and was far more helpful.

85. I requested F medical records from the hospital, and felt I was being given the run around in the beginning. I resubmitted my application and put my job title on it hoping that it may make a difference. I am yet to receive a response.

Section 8. Other Issues

86. On behalf of all persons infected and all those families who lost their loved ones to infections, I would like the Public Inquiry to hold those responsible and accountable for their actions. They should accept liability and admit to their mistakes. People are still suffering and mourning their loved ones.

87. We have all been forced to continuously fight to get some kind of acknowledgment. We deserve closure and to know why those responsible made such poor decisions and why the risks of these products were not communicated. It isn't rocket science, even a lay-man would know that it is risky to treat patients with blood which originates from homeless people and prisoners. They have destroyed thousands of lives; the least they can do is accept responsibility and apologise.

88. You would think after eight years it gets easier but it doesn't. Every time I have to describe what happened, I have to relive my past and in making this statement, I have had to relive it all over again.

89. Despite this, it is so important that our stories are heard as there needs to be justice for the infected and the affected. It wasn't just losing F and B that was devastating, but also losing their mother who spent her whole life dealing with her children's infections. Just as you think you might be able to progress and move forward it seems someone else dies and you start the bereavement cycle again, still not healing from the previous deaths.

90. In terms of following the Public Inquiry, I have been very active on social media and have spent much time watching oral evidence online. I am very well read on the matter and have gone out of my way to purchase literature. I have also kept any letters I received from the government bodies giving updates.

Anonymity

91. I wish to remain anonymous for the purposes of this Inquiry.

92. I do not wish 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

Dated: 24 September 2019