Witness Name: GRO-B
Statement No: WITN5696001
Exhibits: WITN5696002 - 010
Dated: 21 June 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I GRO-B will say as follows:

Introduction

1. I am 54 years of age and was born on the GRO-B 1967. I suffer from severe Von Willebrand Disease (type 3), which causes spontaneous bleeds, most particularly into my various joints.

2. Both my parents were tested for Von Willebrand Disease however both tests were returned negative. In the 70's, the tests were not very efficient on very mild cases, therefore both parents must have at least had a mild strain of Von Willebrand Factor for them to have a child with severe VWD. I am the only child out of their five children that Von Willebrand was passed down to, and I have a severe form of the condition.

3. I contracted HIV and Hepatitis C as a result of receipt of contaminated blood products received during my childhood. I was also given a product from a donor who died of variant vCJD.

Section 2: How infected

4. At 6 weeks old I suffered a brain Haemorrhage for which I was rushed to Pinderfield Hospital, where I underwent surgery to remove a blood clot from my brain. I lost the use of my left side. Over time, I slowly started regaining

movement in my left arm and left leg. I suffered that stroke due to Von Willebrand's.

5. At about 7 years of age, my parents started to notice a problem with my sight for which I was referred to Leeds General Infirmary. My parents were informed that the sight loss was a result of a that stroke when I was 6 weeks old. I now have reduced sight in my right eye, which is often referred to by Optometrist's as a lazy, which I have to correct them. The vision in my left eye is good.

6. My ulnar nerve is permanently damaged. This has resulted in loss of sensation in part of my right hand and I get muscle spasm and clawing of the right hand and fingers. I also suffer from elbow joint issues. I had a fistula in my left arm aged 16.

7. I have severe problems with my veins. Therefore, injections have always caused problems due to my veins collapsing. **WITN5696002**

8. I have had microwave ablation twice and a Hysterectomy. **WITN5696003**

9. I have suffered from a huge amount of joint problems which have resulted in surgeries from 1991-2006. I have had a right elbow replacement, multiple surgeries on the left ankle including an ankle replacement in 2006 and a right hip replacement in 2015 and Girdlestone in 2016. Due to the infections I have not had a hip revision and I continue with a Girdlestone on the right hand side. Unfortunately, my left ankle was fused. My right ankle joint is faulty and it will have to be removed at some point. I have been told this will cause further serious mobility issues as the bone around the joint is damaged and the pulse in my foot is already weak. **WITN5696004**

10. Due to my surgeries, I have lost leg length of about 3.5cm's and wear a platform to be able to walk, balance and to reduce bleeds. The multiple surgeries on my lower limbs have left me with nerve and circulation problems in both my legs and feet. I have had various washouts due to such infections. I have no left hip

and my left ankle joint will require surgery due to the faulty part with more leg height loss and possible mobility loss.

11. I suffer from recurrent infections, which are common following most of my orthopaedic surgeries. I have even had to have a hip implant removed due to an infection. I have contracted Sepsis several times; once in 2015 following my hip surgery when I was admitted twice with infections in both my legs. Septic shock ensued as there was a fear that the infection had spread to my heart, I was transferred to intensive care. At no time during all my surgeries was there any discussion with me about the reasoning behind every infection that followed, where I believe those infections are related to my immunocompromised status. I was simply prescribed antibiotics. I am still currently suffering from an infection in my elbow for which I am undoing biopsies under the care of Dr Vollands. I have had to undergo various elbow joint washouts and replacement of metal parts due to such infections.

Treatment /Care/Support

12. My treatment history consisted initially of Cryoprecipitate which worked fine for any surgeries or spontaneous bleeds that I had. Cryoprecipitate achieved the necessary clotting. I attach my treatment record to date, **WITN5696005.**

13. During the extraction of teeth at age 10/11, Dr Swimburn utilised a combined Factor VIII and Cryoprecipitate approach to treatment, where afterwards she informed my parents that such an approach would be the preferred treatment option into the future for any surgery. **WITN5696006**

14. From the age of about 14 i.e., 1981, for reasons unknown, I was switched to Factor VIII concentrate. I believe Factor VIII concentrate was the cause of my HIV infection. **WITN5696007**

15. I was concerned about the amount of schooling I was missing and the affect it would have on my GCSEs. Unfortunately, instead of improving the efficiency of receiving treatment at Hospital (e.g. patients having to sit for hours in

Pathology, because doctors are in clinic or on the wards) it was decided by my Consultant that the best way to deal with this was to go to hospitals closer to my home for prophylaxis injections. Therefore, the first hospital that I received treatment was GRO-B General Infirmary Accident & Emergency Department.

16. The doctors in A & E struggled to access my veins and majority of the time GRO-B had to arrange transportation to St James' Hospital. I was never transferred before 5 pm, so always attended A & E at St James. Doctors at St James always were successful in accessing my veins.

17. My time of receiving treatment at GRO-B Hospital was short lived. On my last visit I was seen by a doctor who was inadequate. He insisted on trying veins that needed to be rested because of overuse. He continued to inject my Factor VIII into veins that had blown/collapsed. On his final attempt all the signs were there that the vein had collapsed. I asked him to stop as I couldn't take anymore. If you try and inject Factor VIII into a vein that's collapsed, you will end up enduring an intense sharp pain.

18. Eventually he said he was going to take the needle out and try somewhere else. I relaxed as he attempted to inject me once again. I jumped out of my seat and was suffering yet again another sharp pain in my arm. I was absolutely furious I yanked the needle out of my arm and started to rant loudly about what he had just done to me. As I looked up the doctor was leaving the cubicle very quickly. A nurse who I liked, was sent in to talk to me and she was able to calm me down after that horrendous ordeal. During my time in A & E at St James', I always felt that the doctors listened to me and my injections were trouble free.

19. The news of my reaction at GRO-B Hospital reached Dr Swimburne who was not impressed. I explained that I had no intention of returning to that hospital and it was agreed that I could return to Leeds for my treatment.

20. A couple of months later Dr Swimburne confirmed that they had arranged for me to go to Pinderfields Hospital Wakefield for my Prophylaxis treatment. I told

her that I was not happy to which she explained that my experience would be different this time. I agreed, on the basis that I would be going to the Haematology Wards and my injections would be carried out by Haematology doctor.

21. The Doctors were very good at accessing my veins, unfortunately I was having to wait longer and longer every visit for my treatment. I always arrived on the ward at Pinderfields hospital between 1 - 2 pm. I waited in the day room for the Dr to arrive with my Factor VIII injection. If there were no beds available my treatment was given in the day room.

22. My final visit to Pinderfields Hospital proved to be a very long day. I arrived at my normal time before 2pm and found the nurses and doctors to be very busy. Around 6pm I complained that I was thirsty and hungry and was given a cup of tea and biscuits. The doctor arrived with my injection around 8pm and apologised because of the long delay and gave me my injection. I then had to wait for transport home.

23. Luckily for me an ambulance had brought a patient from Scarborough Hospital to Pinderfields and so I managed to get home before 10pm. Both my parents were concerned and angry at the time I arrived back home from the hospital and my explanation didn't improve their mood at all.

24. Next day when I arrived home from school my mother informed me that I was going back to St James hospital for treatment and that my medical advisors would not be sending me anywhere else.

25. During a conversation with my medical advisors in 1981, it was suggested I trial home treatment. I was given Factor VIII concentrate to help my blood clot.

26. Subsequently, I was put on Haemate-P, then Wilfact and then then Voncento from 2018, which can be seen from my treatment record at WITN5696005 above. The latter, managed to sustain the best response levels, and I have therefore remained on it. I now only take 3 Prophylaxis injections per week.

27. The HIV diagnosis was delivered to me in August /September 1986 when I was alone at St. James Hospital by the Haemophilia Nurse and I was only 19 years of age. I have enclosed test results **WITN5696008.**

28. Dr Swimburne was my treating Histopathologist up to my HIV infection and thereafter I came under the care of Dr McVerry, Consultant Haematologist who monitored initially my T cells count.

29. At the subsequent attendance at hospital, I was told that I had been informed of my HIV diagnosis when I was 15 years old in 1982. This is not true as I was never told about this diagnosis nor was I capable of being treated for HIV in 1982. At this consultation, the Haemophilia Nurse also informed me that I should never have been infected with HIV if I had been kept on Cryoprecipitate.

30. I was aware that there was another Von Willebrand's disease patient at St James Hospital at the time, and that patient was kept on Cryoprecipitate. I can see no plausible explanation for switching me to Factor VIII concentrate with its additional AIDS risk at such a young age and at such a time. As a result of this switch, I was infected with HIV and the other patient was fine.

31. Leeds Infirmary wrote to me to inform me and my family that a talk was scheduled in the coming weeks, to discuss contaminated bloods being traced back to America. This talk occurred when I was aged 16/17 years. It was assumed by my parents that the blood products that had been received by me were from UK donors. When my parents and I attended the talk, Dr Swimburne held the floor. It was mainly about the AIDS scandal in America. I did not then know the relevance of the meeting or understand what was being said. We left confused, yet I did not question why we had been invited. No one there in attendance, patient or family members, asked questions.

32. I was also infected with Hepatitis C through receipt of the contaminated blood products. I was not advised of this diagnosis until 1995 and only then when I questioned it. I was advised that I became infected, but the infection cleared itself. I had various surgeries going on at that time, but recall Dr McVerry

assuring me that everything would be fine and to get on with my life. **WITN5696009**

33. Given that I had also been given a product from a donor who died of vCJD, I became part of the variant review. To date, the results have not been forthcoming. As far as I am aware the hospital was advised not to panic their patients. This potential serious health consequence continues to weigh on my mind. **WITN5696010**

34. In 1986 aged 19, I suffered an internal bleed and had to go to A&E at St James' Hospital. I remember it was the weekend. I was sent home and was not there long when I received a call at home, from a nurse at the hospital to tell me that the treating doctor has pricked himself with my needle. The nurse asked me if I had been tested for AIDS. The Haematology Department had refused to give this nurse any information about myself due to patient confidentiality.

35. The following day, I returned to the hospital to have blood tests carried out by the Sister. I was informed that she would contact me if the HIV test was positive.

36. I was in a relationship with my then boyfriend and he grew concerned when a week had passed with no calls from the hospital. I attended my outpatient appointment and decided to explain what had happened to the Haemophilia nurse. I remember her being quite angry with me. She was not happy with me that I had returned to the hospital to have my bloods checked when I was already aware that I have HIV. She advised that I was informed of my HIV by Dr Swimburne when I was 15. She said that all patients were notified at that time. This information was wrong for the reasons outlined above.

37. I had recurring nightmares about dying since that day and suffered panic attacks post HIV diagnosis. No counselling was offered to me. I was left to relay this information to my parents. I delayed informing my parents for at least one year. My parents knew I was out of sorts and started probing as to why, which resulted in the disclosure of my HIV diagnosis. Also, they may have been aware of Solicitors correspondence which I had received.

38. Had it not been for this attendance at St James' A&E, I dread to think when I would have been informed of my HIV status.

Consent

39. We were never advised of the risk of blood products or given any treatment options. Clearly, if my parents or I were aware of the risks then there is no way we would have consented to this treatment.

40. It makes no sense why the Hospital Authorities switched my treatment from Cryoprecipitate to Factor VIII concentrate. I just recall being told by the registrar that there will be a switch. The matter was never discussed with my parents and no options were given. What is clear is that this should not have happened as it was an extremely high risk decision that was unnecessary and contrary to then standard treatment policy resulting in my life being destroyed. I refer you to the NHCD's recommendations at that time that ought to have been of paramount consideration in relation to my treatment.

41. I should never have been prescribed home treatment but was not given any choice in the matter. As someone with significant problems with my veins, it was not surprising that my veins started to collapse. I used to be supervised by the matron at school when I was doing the injections. Given the issues with my veins I struggled with home treatment, and then would have to attend hospital. Consequently, it would have made more practical sense to have continued on Cryoprecipitate as same would have been administered in Hospital.

42. If the hospital claim that I was informed of my diagnosis when I was 15, then what legal permission did the Hospital Authorities have to provide such a serious and life altering diagnosis to a minor in the absence of my parents.

43. There was no consent obtained to being part of the vCJD review or for the testing in relation to the product received from the donor who died from the

disease. I understood I had to go with it i.e., partake in it. I did not even know I had been given this product which carried such vCJD risk.

Impact

44. Since my HIV diagnosis I have noticed myself and other patients being treated differently as Hospital inpatients. We were treated as if we were second class citizens. This has been very upsetting and has added further stress given that we found ourselves fighting for even basic Hospital entitlements. For example, excessive zeal to advise Hospital staff of infection risk at the expense of my dignity and privacy relating to my HIV status. Also, the use of curtains which did nothing to preserve confidentiality or maintain our privacy in anyway. I decided to join and I am part of the Haemophilia Action Group to work with Haemophilia staff to try and improve services for all bleeding disorder patients.

45. I became a Patient advocate in 2017/18. The aim was to try and improve bleeding disorder patient's services within the Leeds Trust. In 2020 I emailed the Haemophilia Nurse to raise concerns over the delay in appointing a Haemophilia Psychologist. I felt that Leeds needed this facility to ensure they keep their Comprehensive Care status. The Public Inquiry was also taking its toll on the patients infected and affected. I was contacted days later but the Haemophilia Nurse told me that the application for funding had been refused, due to COVID 19. No new funding would be awarded until the pandemic was over. I explained that that wasn't acceptable, and after a discussion the only way I could get the hospital to overturn its decision was to make a formal complaint. I made my formal complaint as to why a psychologist is essential for bleeding disorder families. I explained how a bleeding disorder can also affect your mental health. I also explained exactly what actions I would be taking if they refused to fund a service that is desperately needed. My very blunt email got the decision reversed 24 hours later.

46. It really does upset me that patients have to fight to obtain/keep services that the hospital should be providing in the first place.

47. I feel I am no longer the easy-going person I once was. I now worry more and get easily agitated. I feel like I have lost control over my life and the ability to make plans freely.

48. Due to my mobility issues and the bleeds into my elbows and various joints, I have never been able to live a normal life. Adaptations had to be made for even the most basic requirements. For example, from a young age my parents had to buy electrical equipment for me to pursue my passion for baking. I was unable to par-take in so many of my interests, like P.E at school etc. The HIV and Hepatitis C and the treatments for these infections further restricted my ability to deal with day to day life or pursue my interests. They have created further significant medical problems due predominantly to infection which I am battling with to date, such as the recurrent joint infections. I have had to exhaust my limited energy on fighting for basic human rights, against hospitals, McFarlane Trust etc and now for justice through this Inquiry.

49. A lot of my school years were spent in hospital. I recall spending very little time at High School. Despite this and low grades in my GCSE's, I returned to college in 1990 where I enrolled for a GRO-B course, then a Higher National Diploma in GRO-B, which was followed by a top up degree in GRO-B GRO-B in 1997. But for my viral infections, I would have achieved more qualifications and a career.

50. Due to my illness I was unable to secure any employment. Despite obtaining a degree I did not get any career benefit from it. During 2011 – 15 I partook in volunteering work with GRO-B, a mobility charity. I worked 1-2 days per week in their benefits department and would assist clients in completing blue badge applications. Due to my history, I always felt the need to give back and I felt great pride in doing this job, plus it made me feel like I was not just surviving the effects of my disabilities. I had planned to do NHS Management or to be a patient advocate but unfortunately, I was unable to pursue my plans due to my ongoing deteriorating health issues. To this day I struggle to advance any work situation, even for my own benefit.

51. I suffer from treatment and HIV side effects such as Diarrhoea, migraines, vomiting, fatigue from my HIV medication. I have developed slight kidney damage and my various Consultants consider these problems become more prominent when my body is fighting the infection.

52. Due to the Sepsis in 2015, I was put on IV antibiotic medication for almost a year together with anti-sickness medication, yet I was still being sick within hours of my anti-viral medication being received. I was unable to eat and even the smell of food made me feel ill. This resulted in my losing over 10kg in weight and then being prescribed energy drinks to address the weight and energy loss.

53. In July 2018, I was having problems with my port-a-cath but was otherwise fine but had had blood tests including blood cultures. The next thing that occurred was an emergency ambulance at my doorstep which had been called by my doctor from the Haematology department which I knew nothing about. I was at GRO-B Boat Racing in GRO-B and was being told to come home and I had no idea why. Upon being taken to the hospital, I was informed my blood results were very high. This is an example of regular situations that I have found myself in due to the uncertainties associated with the deterioration in my health which resulted in my having little control over my life.

54. My boyfriend was employed as an GRO-B. He was terrified that he would lose his job if his employer became aware of my HIV illness. On reflection, we broke up many times due to that pressure but we got through it and our relationship became stronger. Colleagues would constantly ask what type of medication I was on. These interrogations him under a lot of pressure and so it eventually got too much for him. He lost weight, he was stressed, and our relationship was affecting his work. He was terrified that if my diagnosis came out, it would not only impact his life, but that of his parent also. He walked away from our relationship. At the time, I felt responsible for what he was suffering due to my illnesses.

55. Months after our relationship ended, the colleague who had asked him so many questions, drove me to the hospital with GRO-B. Within minutes of being in the Ambulance I was asked if I was HIV positive. There was no logical reason for him to ask. I lied and told him as far as I was aware I didn't know of any patient being infected with HIV at Leeds, but why would the hospital tell me if anyone had been infected? I then added that hopefully nobody has been infected in Leeds.

56. After this incident, I stopped going to the hospital by Ambulance. My Dad had to take time off work to take me to the hospital. I explained to my parents that even though our relationship was over, the GRO-B would not leave my ex-boyfriend alone. I did explain the exact reasoning behind this as my parents were unaware of my infection status at that time. I had lost the only person who knew and who was helping me come to terms with my diagnosis.

57. I am unable to commit to relationships. I felt numb and fearful of the viral transmission risk. I reconnected with my boyfriend some years later and rebuilt a friendship. Although he was HIV tested and was fine, his life was a mess and all relationships he was involved in following our relationship were somewhat dysfunctional. That was my last serious relationship. Had the relationship with my boyfriend survived my illness, he is the one that I would have chosen to build a future with and with whom to have children. I always wanted a family, I feel that this opportunity was robbed from me by HIV infection.

58. I went off the rails when my relationship ended. I was out partying and drinking a lot to the extent that my parents noticed and became concerned. I could not articulate my problems. I would snap at my parents. I feel that they were just waiting for something to happen so that they could pick up the pieces.

59. When I commenced my triple therapy in 1995, the side effects to this treatment were awful – migraines, vomiting, diarrhoea and exhaustion. I had viral escape and toxic reaction. This treatment alone impacted upon my life and is not something that I would want to go through ever again.

60. I was petrified to tell anyone about my HIV status in case the news leaked out. I maintain that secret to this day with most people. I live a a lie with this secret.

61. Out of the blue, a letter from the Haemophilia Society arrived at my home, it requested that I contact them for the purposes of making an appointment. My mother knew about the letter and insisted on attending with me so that I wasn't alone. I made my mother swear not to tell anyone. Eventually, as time progressed, my whole family knew, and they struggled with it. My niece and nephew did not know how to deal with it and their fear was apparent from the beginning. My sister struggled with it the most. It was only when she began working for GRO-B charity, that she started to understand what I had been through or suffered.

62. I have suffered infection after infection which must in my opinion be the result of the HIV and Hepatitis C having caused my immune system to be compromised, making me much more susceptible to other infections. This has been very difficult to deal with and I am constantly worried when undergoing any surgical procedure, as there is a substantially increased risk from these infections. Also, these infections cause an exacerbation of my Factor VIII levels, which become dangerously high with its own intrinsic risks.

63. HIV is both a life-altering and life-threatening illness which has always been the dominant issue relating to the quality of my life, especially my physical mobility.

64. I lost leg length due to all my hip operations and subsequent infections. The infections continue to lie dormant as efforts to control it were never achieved. I now wear a platform on my right leg given that it is shorter than the other leg.

Financial Assistance

65. In 1995 I secured a mortgage with Nationwide to purchase my bungalow through the McFarlane Trust. Strangely there was a clause in the terms that stated my parents could not reside in the house until the mortgage was cleared and that they could not go on the deeds. After some communication, my parents

did eventually reside with me, but were made to sign a document to say that if I died, they would move out. They only had a temporary right of residence. My sister moved back from GRO-B to live with me to provide support and she had to complete numerous questionnaires and forms. Anyone coming to my house to stay had to sign a form to the same effect. My sister subsequently moved out due to the hassle of the continuous assessments by the McFarlane Trust/ Mortgage company.

66. For my HIV, I received a payment of £20,000 from the McFarlane Trust for which I was encouraged to sign a letter stating that I would not take any legal action. Although I signed, I was not satisfied about this as I always wanted answers as to why I became infected.

67. I am in receipt of a monthly grant from McFarlane Trust which started at £300 and has since increased to £375 per month. A further one-off payment, which I believe was in the amount of £16,000. has been paid to me. I was given a further option of applying for a grant, which was effectively an interest free loan that the McFarlane Trust would deduct a monthly amount off the payment until the loan was repaid. I did this on a few occasions but had money stopped from my monthly McFarlane payments, causing financial problems for myself as I was using the McFarlane payments to make monthly mortgage payment and discharge utility bills.

68. I had applied for a grant to replace windows and doors which were in a poor state. I was advised by McFarlane Trust that the grant is to replace one window and one door only. They asked me which window/door I wanted to replace but I advised them all of them needed replacing. The grant was refused, and I was told my only option was to take out a second mortgage for which they would pay the legal fees. One year after I started paying for the primary mortgage in March 1995, I had no option but to take out a second mortgage of £5000 on a 25-year term. This did not make financial sense.

69. Around 2008, I applied for a respite grant from the McFarlane Trust. They decide what respite venue you can attend. This break ended up a disaster as

another resident had run their wheelchair into my leg which resulted in an ankle bleed. I had to be rushed back home. I ended up complaining to the Trust for dictating what respite beneficiaries people are entitled to. In 2011-2017 the rules on discretionary grants were made even more stringent and despite all I was going though due to the HIV/Hepatitis C, I did not qualify.

70. I received a settlement via solicitors recommended by the Haemophilia Society. I signed the waiver in respect of the compensation that I received, which looking back now was only due to the fear that I felt under pressure due to other persons saying where if I did not sign it, no one would get any Compensation payment as I had been advised of its 'All or nothing' nature. Back then, nothing was clear, I was unaware what rights I was waiving. I was also young and in a bad place emotionally at the time and therefore just agreed to the settlement. I would not agree to such a settlement if I had to make the same decision today as I now appreciate that I ought not to have been infected. Also, the reality is that my life has been destroyed by HIV.

71. I am currently on the following benefits:-

- EESA (enhanced employment support allowance) - £388.60 fortnightly
- Disability Living Allowance (with mobility and care component) £595.40 p/m

72. I was taken off Disability Living Allowance in 2020 after being told by DWP that I had to apply for Personal Independence Payment (P.I.P.). It was awarded at the same level as before - Higher Rate for both Care and Mobility components. It was awarded as an ongoing entitlement instead of the Indefinite level given for DLA.

73. I have the following mobility aids as a result of my issues:-

- Disabled ramp – paid by social services
- Rise and recliner chair – self funded
- Memory foam mattress – paid by McFarlane Trust
- Aqua Lift bath- paid by Mc Farlane Trust

- Bed lift – paid by social services
- Indoor electric wheelchair – supplied by social services
- Large mobility scooter – self funded
- Light weight folding press button mobility scooter - paid by McFarlane Trust
- Grabbers – supplied by social services
- Sock aid – supplied by social services
- Leg lift – supplied by social services
- Long handled washing aids – self funded
- Disabled trolley -supplied by social services
- Perching stool -supplied by social services
- Electric motor to electrify my garage door - paid by McFarlane Trust
- Car o lift 90 (car hoist – partially funded by McFarlane Trust, balance self-funded
- Electronic kitchen aids – self funded
- Panic alarm fitted as she has had a lot of falls due to mobility issues since 2015.

74. I will point out that the process for getting the above items paid for by the McFarlane Trust was nothing short of stressful. In 2011/12 the Trust wrote to all beneficiaries and said they had a lump sum of money that didn't have to be returned to the Government. They had decided to give grants to beneficiaries to pay for essential requirements such as work to be done on homes and disability equipment. I asked for the above listed items (amongst others) and following their assessment, approval was granted as they agreed the items were necessary for my needs.

75. Once their reports were submitted, I received a letter stating they had underestimated what people would need and were therefore only going to focus on essential requirements. Accordingly, they only approved two items and everything else was ignored without any explanation. I was angry and had to purchase my rise and recliner chair making a minimal deposit, as this was an essential item for me. I had to pay the remaining balance within 6 months to avoid any interest. I purchased a scooter using money I inherited from my mother. These grants were finally sorted in 2013. I consider the Trusts

behaviour and actions were inappropriate and in disregard of my personal suffering and requirements due to HIV infection.

76. The same grants were offered by McFarlane Trust in 2017/2018. By the end of 2018, the Trust advised that due to the Public Inquiry, they were donating the remaining 4 million to Terrence Higgins Trust for counselling and the beneficiaries can contact Terrence Higgins for counselling. I am struggling to understand this, as in April 2019, I found out about the Red Cross offering counselling for the infected and affected.

77. I received a payment from EIBISS in the sum of £18,000, broken down as £1898 p/m for HIV plus discretionary grant and £341.33 p/m for Hepatitis C stage 1.

78. I had asked my Consultant to complete my application for the Skipton Fund based on having received a letter informing me of the entitlement for people who had been infected with Hepatitis C. He found it amusing and said he could not complete the form as I was now Hepatitis C virus clear. I recall him asking if I would rather be infected and paid out or not infected and not paid out. Of course, I said, 'not infected' and went home. I continue to suffer debilitating fatigue which could be caused by my past Hepatitis C viral exposure and/or the consequence of HIV infection.

79. I still applied to the Skipton Fund, but my application was refused on the basis that there were never two positive test results in a row, so I was told I was not entitled to anything. I had always believed that I had been Hepatitis C positive. It was only with the support of a Haemophilia Nurse Specialist, that I was able to produce evidence in the records showing that my test results were high from the end of the 1980's to early 90's and my LFT showed that my liver was fighting an infection, that my appeal was eventually successful and I received a payment of £20,000.

Other issues

80. The Factor VIII Concentrates that I received were clearly contaminated Factor VIII Concentrates which have had a significant detrimental impact upon on my life, and most particularly my own life path has been irretrievably altered. Even now I am suffering . At present, surgery is being considered for my faulty ankle joint which is loose. I will have to make an important a7 decision as to whether I proceed with surgery, because if it does not work, I will end up immobile and in a wheelchair, where this problem in my opinion arises from the infections due to my HIV status. Surgery is a higher risk factor for me now given my weakened immune system and susceptibility to infections.

81. I am worried about what the future holds for me. My father died in 2006 and mother passed away in 2014. Three of my 4 siblings are over 70 years of age. Life is a struggle for me day to day and I may no longer have such a strong support network in my family going forward as time itself will takes its toll upon my own family.

82. I am not sure how I am going to cope, if my health and mobility deteriorate further because of the HIV and Hepatitis C infections constantly resurfacing. I do not consider the health and social services available are sufficient at present to cope with virally exposed patient requirements, and it concerns me what will happen in the years to come.

83. EIBSS makes you jump through hoops and as far as I am aware, they do not offer long term help for the infected. Respite breaks are not enough for people who need long term healthcare, and this has been my biggest concern since my diagnosis. I do not want to burden my family members if my health further deteriorates and I become utterly dependent.

84. There are a lot of questions to be answered in the pursuit of justice. I do not consider I have been appropriately compensated at all for a situation that has ruined my life. I want to know the answers to the following questions:-

1. Why my concentrates where switched without any need or justification.

2. Why, as a child, was I exposed to viral risk and infected with both HIV and Hepatitis C?
3. Why I was prescribed home treatment?
4. Why there was a delay in diagnosis for both HIV and Hepatitis C?
5. Why was my HIV diagnosis was delivered to me when I was alone and not whilst I was I in the presence of my parents or when I was accompanied with support?
6. Why was I told they were using UK products?
7. Why were imported U.S. plasma derived Factor concentrate utilised for a Von Willibrands patient?
8. Why was I not adequately compensated in a manner to reflect the trauma I experienced?
9. Why the McFarlane Trust behaved in the way they did and made the decisions they did?
10. Why no appropriate financial support has been provided to me after my diagnosis?
11. Why do I have no answers in relation the VCJD trial?

Statement of Truth

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

Signed GRO-B

GRO-B

Dated 21/06/2021