Witness Name: GRO-B
Statement No: WITN1300001
Exhibits: 0
Dated: 28th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B GRO-B. I am GRO-B years old and I live at GRO-B GRO-B. I am GRO-B and I have never been in a long-term relationship. I have never been employed although GRO-B I have occasionally undertaken GRO-B support when I feel well enough. I spend most of my time at home. My mother has been my carer and has only ever worked on an ad-hoc basis. My father is self-employed (now semi-retired) and GRO-B.

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

3. I was diagnosed with severe GRO-B. I GRO-B GRO-B and needed hospital treatment. The tests showed I had low levels of Factor VIII. I was treated with Cryoprecipitate.

4. I received Factor VIII on demand from the time I was diagnosed. I was treated with Factor VIII concentrate and from GRO-B onward, I was apparently given heat treated Factor VIII. Prior to that date I was treated with non-heat treated Factor VIII.

5. I was treated at GRO-B GRO-B and GRO-B. I also saw GRO-B GRO-B GRO-B

6. My parents were aware of the risk of AIDS from the very start and were very concerned about me being treated with Factor VIII.

7. As a result of receiving blood products, I have contracted the Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV).

8. I was diagnosed as HIV positive in GRO-B when I was GRO-B. I was first tested in GRO-B and the result was negative. I was then given heat treated Factor VIII because it was considered to be safer. My parents chose not to tell me about the diagnosis and the doctors agreed that this was a wise decision.

9. In GRO-B I was tested for Australian Antigen which is Hepatitis B.

10. In GRO-B, my immune system was severely compromised by the HIV infection, the doctors decided that I needed to take the new antiviral medication that had become available. Therefore I needed to be told about the HIV infection.

11. I remember the doctors saying to my parents that they needed to have a talk with me about something before the next appointment. It was shortly after we left the hospital and got back to the car that I asked my parents what they needed to tell me, it was at that point they told me I was HIV positive.

12. My main concern was that I was going to die and I asked them "what happens to people with HIV?". It was explained to me that nothing had really changed, apart from my knowledge of the infection. I think they told me not to go kissing girls behind the bike shed, although nothing else was really said about transmission risk at the time.

13. I was also told that it had to be kept a secret from everyone because of the fear and stigma surrounding the virus. Only my grandparents (on my mother's side) knew, it was kept from all other family members.

14. I seem to remember dealing with the news on my own. I think some more questions were asked, but on reflection there was very little emotional support offered from my family and we didn't really talk about it. I think my parents were also struggling with the situation and finding it very hard.

15. At the next appointment the doctor asked if I had been told and I gave him my limited understanding of the situation. The conversation then went straight to talking about treatment and how that might make me feel (physically from side effects).

16. I do not remember being offered any counselling; however, reading the letter from GRO-B to my GP, contained in the medical records I have received, it indicated that counselling was offered to me if my parents thought it necessary, although I never did receive any support of that kind.

17. I started Zidovudine (AZT) an HIV antiviral, on the GRO-B. I was GRO-B years old. It consisted of three or four tablets a day for two months.

18. Perhaps because I was so unwell during my teenage years I was never informed by any healthcare professional, or my parents, about the risks of HIV transmission through sexual intercourse. I probably found out more myself online as the internet had just become available to me.

19. I remember being told to be careful if I bled because the blood would be infectious. This scared me because I thought my parents might get the virus from me or anyone helping me should I cut myself.

20. Nobody at school (friends or teachers) knew about the infection so I felt responsible for them and would feel the need to protect them from the virus.

21. I was tested for Hepatitis C (HCV) in GRO-B (seemingly without my knowledge) at GRO-B which confirmed I was HCV positive. The letter from Doctor GRO-B states that no treatment was necessary at that time.

22. I remained unaware of the HCV infection, until GRO-B, when I developed testicular cancer and needed surgery to remove the tumour. During one of the assessments prior to surgery, one of the doctors told me that I would need a certain kind of treatment because of my HCV infection. I did not know what to say; I felt stunned at hearing this, because before this point my family knew only of the HIV infection.

23. This was truly devastating, and coming at a time when I was dealing with the diagnosis of testicular cancer. This further impacted my mental health and has stayed with me ever since.

Section 3. Other Infections

24. I have been told I am at risk of vCJD.

Section 4. Consent

25. I do believe that I was tested for HCV without my knowledge or consent and not told the results when they were confirmed as positive.

Section 5. Impact

26. Living with HIV and HCV has resulted in me suffering from chronic anxiety, social anxiety and depression, as well as symptoms of depersonalisation, derealisation, PTSD, low self-esteem, low self-confidence and low self-worth.

27. I struggle to learn new things and my memory is poor. I can struggle to think and plan things in my mind. I can feel dizzy and light-headed.

28. I have had chronic fatigue which has severely limited what I can do and resulted in me spending a lot of time at home, isolated, apart from being with my parents.

29. I was given AZT at the age of GRO-B to try and control the HIV virus that was taking hold in my body. I felt very scared taking the medication because the doctors had told me of the possible side effects. I was still struggling to come to terms with the diagnosis and that I was living with HIV.

30. I seem to remember the medication had to be taken at regular intervals throughout the day, this meant that I had to take a tablet just before going into school in the morning and then again in the car as soon as I left school in the afternoon.

31. After a few months the side-effects were severe enough to make me want to stop taking the tablets. I had severe nausea and I did not want to eat. Eventually, I agreed with my parents that I would not take the drugs and just live with HIV, because at the time I was not getting any illnesses associated with the virus.

32. Until about the age of GRO-B my health was relatively good, although I had to cope with repeated bleeds and severe pain, due to the Haemophilia. My mental health was also good up until that point.

33. I had a severe bowel infection at the age of GRO-B and as a result I developed Irritable Bowel Syndrome (IBS) which I still have today. I was often doubled-

over in agonising pain on a daily basis from the IBS. I also had to use the toilet on a very frequent basis. This caused haemorrhoids to develop which have continued to be a problem to this day. They are prone to bleeding, often severely, and this limits what I am able to in terms of physical activity.

34. I suffered with constant nausea and sickness, which left me immobilised for a lot of the time, to the extent that I could not continue with my education or lead a normal life as a teenager.

35. None of the medication to treat the bowel problems worked. When Imodium was not working, my GP just kept suggesting I take a higher dose.

36. My low bodyweight was a constant issue and meal times were always a struggle because I just did not want to eat anything.

37. I had no life outside of the illnesses I was developing as a result of HIV and probably HCV that I did not know about.

38. There was a period in the late 1990's when I had Pseudomonas infection. The chest infection caused daily fevers and chills. I was practically housebound the entire time because I did not have the energy to walk upstairs, let alone go outside.

39. I would wake up in the morning feeling reasonably well, but by late morning I began feeling cold and started shivering. I would wrap myself up and drink hot drinks and hold a hot water bottle to try and relieve the chills. By lunchtime I would feel too hot and the sweats would begin. I would do everything I could to cool down. It was often late into the afternoon or evening before my temperature regulated itself, and by this time I felt completely exhausted. This pattern repeated itself for at least a year, until the infection finally went.

40. I also had chronic Candidiasis (Thrush) infection throughout my teenage years. This affected my throat and digestive system. It caused nausea, loss of appetite, changes in bowel movements, mood changes and tiredness.

41. It continues to affect me from time-to-time and I never expect to be free of the condition.

42. When younger I was prescribed Fluconazole by my GP which never seemed to work.

43. There was a period of time when I had a severe cough brought about by another infection. Due to the amount of coughing, blood vessels in my throat were damaged which caused my throat to bleed. This frightened me because it made breathing difficult whenever the bleeding started. I would often feel faint and need to sit or lie down.

44. Again, throughout this period I would often develop anaemia. It is a known side-effect of the drugs I was taking at the time to treat the HIV, which was Combivir and Nevirapine.

45. The anaemia caused, fatigue, tiredness and sometimes difficulty with breathing.

46. I went to hospital several times to receive blood transfusions. I needed to take iron supplements which I bought myself because those prescribed would upset my stomach and digestive system.

47. In GRO-B I found a lump in my testicle and went to the doctor. They quickly arranged a scan and realised that it was a tumour. It was said that it probably happened because of my impaired immune system.

48. I received surgery quickly and made a good recovery. This is when I found out about the HCV infection.

49. I would say that from this point onwards my mental health deteriorated; my physical health began to improve, very slowly. It was around this time that I began a new antiviral drug regime, Kaletra and Trizivir.

50. I found taking these new drugs very difficult in the beginning. Kaletra was a liquid filled capsule and I would find that 30 minutes after taking the drug I would feel light-headed, nauseous, weak and shaky. I would also break out in hot sweats. I could take a couple of hours to fully pass, by which time I was left feeling exhausted and had no energy left. The tablets I had to take twice a day, so had no option to avoid the drugs.

51. I eventually discovered that if I ate a bowl of soup shortly after taking the medication, the side-effects were much less and I would be able to do a little more in the afternoon.

52. Eventually, after many years, the formulation of the drug was changed and it was made into a film-coated tablet. This greatly reduced the side effects and I did not have to stick so rigidly to consuming soup with 30 minutes of taking the tablets.

53. At the beginning of GRO-B my HIV antiviral medication changed to Dolutegravir and Truvada. I was only after stopping the old medication that I realised the ongoing side-effects they were causing. Mostly relating to my stomach and digestion. The discomfort and burning that I would experience went soon after switching medications.

54. The new drugs were easier to take (once a day) although they also came with side-effects. I now dream every night and these dreams can be exhausting and occasionally frightening.

55. I also find that I feel dizzy and light-headed more often. Also my memory is less effective, compared to before.

56. I began seeing a liver specialist after I was diagnosed with Hepatitis C. I would go annually and have blood tests to determine the damage the virus had caused to my liver. I would get so anxious attending these appointments because I knew that if my liver showed signs of deterioration I would have to take Interferon and Ribavirin.

57. The specialist nurse made no attempt to hide the devastation caused to the lives of some of her patients who took those drugs.

58. I also weighed up the potential side-effects against the possibility of clearing the virus. In my case, with HCV genotype 1a, it was around 50%. Every time I went for the appointment there was the hope that 'new drugs' were being developed, so I decided to wait.

59. During GRO-B I was given Harvoni to treat the HCV. I had to continually ask my doctors for the drug because it was not widely available due to the cost. Eventually I was placed onto the list and was able to take the medication which cleared the virus within a couple of months.

60. During the treatment I experienced a worsening of the symptoms/side-effects I had when I started the new HIV antiviral medication. However, I thought that it would not be a problem because of the short duration of treatment. It was also known that Harvoni boosted the effects of the new HIV drugs I was taking, so I decided to persevere through it.

61. The side-effects included severe dizziness, loss of short-term memory, inability to concentrate or think, palpitations, depression, shortness of breath, headache and loss of libido.

62. I was also concerned that the HIV antiviral drugs (especially Truvada) might be affecting my bone density.

63. After I had finished the course of Harvoni, I talked about this with my doctor and she sent me for a DEXA scan. The results showed that I had osteoporosis. It is thought that the HIV, plus the old drug regime and possibly the new drugs, all had an effect. They agreed to put me on the newer antiviral drug formulation Descovy, which was said to be more 'bone friendly'.

64. Twelve months later I had an appointment to see the osteoporosis nurse who recommended that I have my testosterone levels checked. After having testicular cancer, they monitored my testosterone for a few years but then when the check-ups ended, so did the monitoring of the testosterone.

65. My testosterone levels were re-checked and they came back as very low. This would also account for the osteoporosis because testosterone is needed in the male body to keep bones strong and healthy.

66. From that point onwards I had to fight to receive the treatment I needed. My GP did not really believe that I had osteoporosis, and also did not accept the possibility that I might have low testosterone. He agreed to refer me to a consultant.

67. Eventually after five months I received an appointment and was diagnosed with primary hypogonadism.

68. I felt I was on a rollercoaster, in terms of how I felt trying different treatments and then being left without any treatment or support for six weeks when my skin reacted to the gel I had been prescribed.

69. At this stage my mood hit rock bottom. My depression was at its most severe and I was struggling through day-to-day. I felt so distressed and could not see a way out.

70. I did not know what else to do other than do my own research in to possible treatments that might work for me. I discovered that in the USA, testosterone injections were being used and given subcutaneously. This way of injecting is suitable for people with haemophilia. I then provided documentation of a clinical trial and anecdotal evidence to the consultant for her to consider. Eventually, 12 months after the original blood test showing my testosterone was very low, I began the injections and soon started to feel better again.

Section 5: Impact

71. From the time I was first told that I had HIV my worldview changed and I suddenly had this extra burden or responsibility, not only to protect other people and keep them safe, but to also keep this secret from everyone.

72. This made it difficult to develop friendships because in the back of my mind I always felt that I was being dishonest or manipulative with people by not disclosing my status. I felt incredibly isolated because of this. I also did not feel able to have conversations with my parents about how I was feeling. I would not have been fully aware of this and unless somebody had questioned my loneliness and isolation I would not necessarily have associated those words with how I was feeling deep down.

73. Also, because of where I lived, coupled with my very poor health, it meant that most of my life has been spent at home. Whenever I did go out, it would be with my mother or both of my parents.

74. I have found it incredibly difficult to make friends. One reason is that I cannot do the things most people can do and would take for granted. I would always have limited hours within the day when I might feel well enough to go out and do something more social, but due to the crippling anxiety, anything I did do would leave me feeling exhausted afterwards and it could take a couple of days for me to fully recover.

75. It is still the case today that I have very few friends, most are 'online' and I rarely get to see them. I do now have the confidence to share with them my status, although I feel that sometimes it is too much for them to fully take on board or understand, so I usually give them an edited version of how I am feeling, instead of being completely truthful and authentic.

76. I have also struggled immensely with relationships. It is not really surprising because I do not feel that I have much to offer anyone. Living with my parents also puts many off because they see me as dependant and not able to be

self-sufficient or even successful in life. At home, I also lack privacy and the space in which to speak and act freely.

77. I do not fit into society, as I feel so different to everyone else. I struggle to relate to other people's lifestyles. I am unable to do the things that other people do. I have not been able to go on holiday since I was a child, due to anxiety and depression, plus the ability to look after myself when I am not well. I have never owned a passport. I feel that I am judged as a failure and can find it hard to see my own worth.

78. The two people that I have dated and two others, who were a little more than friends, seemed to follow a similar pattern. They liked me a lot at the beginning and accepted all of my health conditions, but within a couple of months contact with them decreased and they began acting differently. Two just stopped talking to me and the other two, with whom I'd been more committed, changed their minds and realised that my lifestyle and needs were not in alignment with their general desires for life.

79. One example is that I worry about sexually transmitted infections because anything in addition to what I have already would undoubtedly seriously affect my health. I am afraid that if I caught any other illness and had to take antibiotics, it could have a terrible effect on the condition of my digestive system, or I might have difficulty clearing an infection due to having an impaired immune system. As a result of this, anyone who wants to have a physical (sexual) relationship with me needs to have a clean bill of health. That is why, if they have not been tested recently, I will attempt to get them to a clinic, ideally before there has been any physical, sexual contact.

80. The first met someone in GRO-B I made an appointment for us to visit the sexual health clinic as he had not been screened for STIs in quite some time. Afterwards, we were taken to a private room and talked to at length about the risks of passing on HIV or HCV through sexual contact.

81. HIV was said to be less of an issue as long as condoms were used, but with regard to the HCV; she told us about myriad ways the virus could be passed on, including passionate kissing. Her advice was to not be too passionate with each other, just to be on the safe side.

82. I thought that I was aware and knew about the dangers and risks, but hearing that scared me so much that I almost became fearful to hug someone, let alone kiss them.

83. It was not many weeks after that we split up.

84. I stopped looking to form a relationship with anyone and shut myself away for a number of years whilst I processed the information.

85. It was 7 years before I met someone else. I was too fearful to go much beyond friendship and kept having flashbacks to that first relationship.

86. I do feel more confident now that I have cleared the HCV and my HIV is undetectable and therefore there is no risk of it being transmitted. However, it is still a major fear whenever I meet someone.

87. Also, I still feel deeply lacking in so many ways. I cannot live independently because I lack the financial means to do so; also due to repeated illness, I do not have the ability to look after myself in those circumstances. I would be fearful about renting a property because I need stability and security, so the thought of the lease ending would cause me great anxiety. It could also take me months or years to find somewhere suitable as I would need a home which is accessible for when my mobility is impaired. Also, I would need to live within a reasonable distance of my parents because they still assist with my Factor VIII injections and also if I should need assistance at any time.

88. The stigma of living with HIV, HCV and severe Haemophilia A since childhood has caused me to behave in a very guarded way, often to prevent other people finding out. I am very suspicious, almost paranoid, when it comes to

people's motives and the reason for them interacting with, or even liking me. Despite desperately wanting friends, I find it very difficult to bond with people because of this. Typically, people cannot accept the level of planning and preparation I need to undertake to maintain a seemingly normal life.

89. My parents were also very aware of the consequences of anyone finding out their son was infected with HIV and they did all they could to protect me.

90. If they really needed to tell someone, or explain why I was so unwell, they would use Haemophilia, or even HCV, as the excuse because these conditions were seen to my parents as slightly easier to admit to and carried less stigma.

91. My treatment at hospital has not been without discrimination. It seems very subtle but something I notice. For example, when a nurse had to insert a cannula and put on two pairs of disposable gloves and was clearly hesitant and nervous about the procedure.

92. Another example is when I have been for a blood test, after visiting the outpatient clinic; I get a frosty reception from the phlebotomist. They know that I have come from the HIV clinic, but suddenly they become talkative and welcoming when they are told I have Haemophilia.

93. In GRO-B I had to be admitted to hospital GRO-B because two milk teeth had broken off and the roots had not come out. The plan was to remove the remaining tooth fragments. I was promised that a local anaesthetic would be used. I was very nervous about the procedure but reassured that it should be relatively pain free. I believe that I was warned beforehand that the dentist and staff would be wearing special protective clothing and not to worry. But when I went into the room I remember that there seemed to be protective covers over a lot of the equipment and the medical team had extensive body protection clothing on.

94. I was expecting local anaesthetic to be used; however, the doctor/dentist decided that it was not necessary. Despite my very loud protest, I was held down and they proceeded to remove the tooth fragments with force. This caused a great deal of pain and distress to me.

95. Afterwards I was inconsolable with rage at what had happened. I felt let down and abandoned by my parents for not intervening (although I now realise they would have been fearful of the doctors) and also that any trust I had in doctors or medical staff was broken.

96. The memories of this still affect me today and undoubtedly affect my relationship with those in the medical profession.

97. My school attendance during primary education was quite good and the only time I missed days were those when I had a more severe bleed and when I had to attend hospital.

98. The first two years of secondary school were okay, although it was always more noticeable when I missed a day or two. I also found myself being placed in the class for pupils who were struggling with education. I felt so frustrated because my classmates were often very disruptive and did not want to learn. I also found the coursework quite basic and I wanted something more challenging.

99. I was forced to leave mainstream education at 14 because my health deteriorated following the bowel infection. I soon lost contact with the few friends I had made in the short time I was at secondary school.

100. Despite having a few hours of home tuition each week I was too unwell to learn very much. As a result I have no formal qualifications.

101. I have never been able to work full-time; instead I am self-employed and choose to do a little **GRO-B** when I feel physically able to do

so. The social engagement is good for me and it allows me to get out of the house.

102. As a family we have always struggled financially. My father has earned just enough to pay the bills, however his income never extended to affording any real luxuries or the ability to amass any savings. My mother was never able to work because she became my full-time carer. As my health deteriorated, with conditions caused by HIV and HCV, I needed more and more support. Even today there are some days when I feel too tired and fatigued to prepare myself food.

103. When I was born, my father worked GRO-B and we lived in a GRO-B. Around the age of six, he fell out with his father (my grandfather) and we were thrown GRO-B. My father then continued working elsewhere GRO-B. When his mother (my grandmother) died in 1997, he was left GRO-B which he sold and used the money to help buy the house we live in today. My parents tell me that some of the money received from the Macfarlane Trust was also used to buy the house.

104. If not for the support of the Trust, we would really have struggled. I would often have to help my parents financially when there was not enough money in the account to pay the mortgage. When there were not such pressing financial issues, I would use the Trust money to buy the extras my father could never afford.

105. The only state benefits I claim are Disability Living Allowance and Employment and Support Allowance.

106. My father is now semi-retired and claiming his state pension. My mother is still a few years away from claiming hers. Jointly, they have no savings. My father has a small inheritance from his late father's estate, GRO-B, which has given him more security and the opportunity to GRO-B.

107. I have saved some money over the years but it is not enough for me to buy my own house. I see it more as a contingency should the family home need repairs or maintenance.

108. I also find myself continuing to support my parents by paying some of the household bills.

109. I do now claim Employment and Support Allowance and this helps with the family income. I am continually anxious about benefit reviews and the constant threat of the money being taken away. I have a Motability car and without that I would be even more isolated because we live in a small village with no practical public transport.

110. I use a lot of my money to buy healthy, nutritious food, vitamin and mineral supplements for myself as well as receiving complimentary therapies such as Acupuncture and a kind of movement therapy which helps with my joint and mobility issues. I also fund my own counselling sessions. Currently, I am in need of extra support and have been visiting weekly.

Section 6. Treatment/Care/Support

111. I understand that counselling was offered to my parents at the time they were asked to disclose my HIV status to me. The offer was never accepted – I do not know why.

112. During the late GRO-B I attended monthly counselling sessions provided by GRO-B based charity, supporting people with HIV. When that support ended I sought my own counselling therapy and now attend weekly sessions.

113. I cannot recall being offered much in the way of psychological support from doctors or consultants. Typically mental health is not talked about during my appointments. In GRO-B when I was struggling most with depression I did mention this to my GP but he seemed to ignore what I had said and made no comment.

114. I do not think support for emotional issues has ever been adequate.

Section 7. Financial Assistance

115. My parents, on my behalf, received the lump-sum ex gratia payment in the early GRO-B They also received regular payments from the Macfarlane Trust until I was old enough to be paid direct.

116. I also received the one-off HCV stage 1 payment.

117. I believe my parents once applied for financial assistance to help with the cost of going on holiday. I also received some extra payments from the Macfarlane Trust to help me pay for vitamin and mineral supplements during the GRO-B.

118. The Macfarlane Trust always seemed to help those affected with the funds they had available; that was until the original staff and trustees left and were replaced with people who seemed more focused on saving the government money, rather than helping those infected and affected.

119. It was at that point the Trust became more obstructive and very difficult to deal with. They made it harder and harder to claim any money from them. Stricter means testing was introduced and something I have always found very unfair is with their discretionary top-up payments: they take into account the household income and not just that of the person infected. So because my parents have an income, the money I now get is significantly less than I would receive if I lived alone.

120. A number of years ago, when the Trust was being run by the new management team, they were asked by the government to disburse their reserve funds as it was considered too great a sum of money for them to hold in a bank account.

121. They decided to employ an independent company (at great expense) to send people out across the country to interview those infected and affected to

identify their needs and determine whether extra financial assistance was required.

122. This was really the first face-to-face contact (albeit indirect) with the Trust that I had had. It was the first time someone was there to listen to me and my family and understand our situation and how we have been affected by this treatment disaster.

123. The person who visited us was shocked and deeply saddened by my story and said that his team were astonished at the lack of support or contact we had had with the Trust. The people sent out to interview beneficiaries, received the years of pent up anger and frustration caused by a lack of support from the Trust or government.

124. During that meeting, I explained that we really needed a new, larger shower/bath because we still have the original 1960's cast iron bath with a shower fitted at one end. The bath is unsuitable for me because it is quite small and although I can get in, because my elbows are damaged with arthritis, I cannot get myself out easily. The bath is also very hard and uncomfortable to lie in. Due to that, I only ever have showers, despite the fact that being in water would be beneficial to my joints and help to reduce pain.

125. The representative working on behalf of the Trust took some photos of our bathroom and went away to write his report, all of which was very helpful and supportive.

126. A number of weeks later the Macfarlane Trust sent out questionnaires and application forms to everyone that wished to make a claim. They were asking us to repeat what we'd told the person who visited. It was as if their visit counted for nothing. They seemed to be making it as difficult as possible. I believe the money offered was also being means tested. In the end, like many others, I gave up trying because I did not have the energy to fight for the extra money or suffer the disappointment of the application being rejected.

127. I received the annual payment from MFET (now EIBSS) for those infected with HIV.

128. I also receive the Special Category Mechanism Payments. It took about eight months to complete the form: I had to get letters and statements from healthcare professionals and write my own account of my situation, It was awarded at the end of GRO-B.

129. I do not understand why it has to be so difficult to get money from EIBSS and why there are so many hoops to jump through. I am excluded mostly from applying from any grant or financial assistance because I have savings, which is a mix of MFT, MFET, EIBSS and DWP money; and when my grandparents passed away they left their GRO-B to my mother and I, which we have GRO-B. So that, combined with the issue of household income excludes me from most support. It seems that the EIBSS expects my parents to support me and for us to look after ourselves.

Anonymity, disclosure and redaction

130. I confirm that I do wish to have anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

131. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed... GRO-B ....

GRO-B

Dated 28th February 2019