Witness Name: GRO-B
Statement No.: WITN0008001
Exhibits: WITN0008002-006
Dated: 20 March 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1980. My address is known to the Inquiry. I am married, and I am not working due to my long-term disability.

2. I intend to speak about my infection with HIV, Hepatitis C and Hepatitis B through the use of Factor VIII blood products for my haemophilia. In particular, I will discuss the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my wife and our lives together.

3. I must also include speaking about the fact that my cousin, GRO-B: C who was also a haemophiliac was also infected with HIV via contaminated Factor VIII blood products, and how C death, as a direct result of his infection, also devastated my family.

4. I must include this on behalf of my cousin, as since he has died, he is unable to represent his own case to this Inquiry. However I wish him, and the circumstances surrounding his death to be represented and respected within this Inquiry. As much as myself, and my own circumstances, I want the Inquiry to remember it is essential to respect and include the sadly, dead infected victims who cannot speak for themselves within this Inquiry.

5. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with drafting my statement.

Section 2. How Affected

6. I was diagnosed with severe haemophilia A when I suffered from a brain haemorrhage in GRO-B 1980 as a 5 month old baby.

7. I was treated at the Birmingham Children's Hospital from the time of my brain haemorrhage up until I was 17 years old, after which I was transferred to the Queen Elizabeth Hospital, also in Birmingham.

8. At the Birmingham Children's Hospital, I was under the care of Dr. Frank Hill who was a Haemophilia Consultant and the Head of the Haemophilia Unit. I believe that Dr. Hill became a Lord after his retirement (or he received some form of title) for his contribution. Dr. Hill would have handled every haemophiliac on the unit - all the children.

9. I was also under the care of Sister Marion - I believe this was her surname, though it is possible this was her first name. I'm sorry I'm unsure of this as I only knew her as Sister Marion and I was a child at the time - she was the Primary Sister on the Unit at the time of my infection. She is now retired.

10. At the beginning of my life, my parents said that I had around 3 to 5 bleeding episodes per week. When I had a bleed, an ambulance would be called and I would be taken to Birmingham Children's Hospital. I was

then treated using Factor VIII blood products, which was administered by the Hospital staff. I understand from my medical records, and from the legal documents I still hold involving the infected blood product legal cases I was involved in, that I was first given Factor VIII on 16 October 1980 and briefly given cryoprecipitate between 1981 to 1982.

11. In July 1986, I began Factor VIII home treatment. The Birmingham Children's Hospital gave this blood product to my Mother to take home and to administer to me as and when I needed it. By the age of 7, I was also injecting Factor VIII into myself.

12. My parents have stated many times to me, and also made statements during the legal cases, stating that to the best of their knowledge, I was only ever treated with Factor VIII products from the company Armour, throughout that period of my haemophilia treatment during the early years of my life.

13. The batches of Factor VIII were quite big - we'd use one batch and then a more up to date batch would be sent to the Hospital. It's likely that a lot of people were using the same batches.

14. Initially the risks of infection were not discussed with my parents before Factor VIII was administered to me. My parents didn't know that blood products could be dirty. They were simply told that the Hospital uses a blood product called concentrated Factor VIII and it is clean and safe to use. With this knowledge and with the fact that I would sometimes be screaming in pain, my parents did not have a choice but to allow the Factor VIII to be administered to me.

15. As I was discovered to be a haemophiliac, my Aunt and the rest of my family were also tested to find out who were the carriers of haemophilia within my wider family.

16. This led to my cousin, C mother, GRO-B (my aunt), discovering that he also had severe haemophilia. C was also born in 1980 and was 6 weeks older than me. We were both treated at the Birmingham Children's Hospital.

17. Around 1984, my parents found out that C my cousin, was infected with HIV. He was around 4 years old. It is possible I would have been on the same brand of Factor VIII products as C but I got away with it at that time and had not been infected up to this date. When I was tested at this point, I showed negative results at that time.

18. Post C infection, my parents were told that it wasn't possible to be infected by Factor VIII anymore after this point, as the Factor VIII was now being heat treated which destroys all the viruses. My Father only found out about the heat treatment as the Hospital had to explain how C was infected to my family.

19. At this point my parents were reassured by the hospital that heat treating the blood products was now being done to make sure I could never be infected in the same way. Therefore the blood products used from that time onwards would be safe and free of viruses.

20. As my family were categorically told that an infection could never happen again, we continued using the Factor VIII. Although you don't have a lot of choice, I don't see anyone agreeing to use dirty products.

Diagnosis

21. On 1 February 1985, I contracted the Hepatitis B antibodies according to my medical records. I was 4 years old at the time. However I naturally cleared this virus.

22. In August 1986, the Hospital told my Father that there was a problem with Factor VIII blood product, which at the time was produced by Armour Pharmaceuticals.

23. On 19 November 1986, I turned HIV positive - I had negative results up until that point. I understand from my medical records, and also from the infected blood legal case documents I hold, that the seroconversion took place between October to November 1986 when I was 6 years old.

24. I believe the fact that I was infected as late as the end of 1986 to be important to the Inquiry, as this shows that the NHS continued to use contaminated products on us even after HIV testing and heat treating was possible. It also shows that the products used on me had not been properly screened for viruses when by that date testing was possible.

25. It is obvious these infected products should have been tested, identified and destroyed! However, obviously this was not done! These dirty NHS Factor VIII products were contaminated! But they were still used to treat us, infecting me at a later date to when my cousin C was infected! This exposes that the NHS and the Department of Health had learned nothing from previous infection events! They simply caused this to happen again and again! I believe this shows appalling levels of negligence!

26. I have a record of all the batch numbers of the blood products given to me (**WITN0008002**). I know I was infected by the blood products produced by Armour Pharmaceuticals as I received compensation from them in a settlement, and Armour Factor VIII products were the only Factor VIII products used to treat me! However I do not know which specific batch exposed me to HIV - I could have been exposed to it from a number of batches as the blood was pooled for the Factor VIII products.

27. On 1 December 1986, my infection was reported to the Hospital and on 8 January 1987, my mother was informed about my infection by telephone. My Mother was very angry about being told this way on the phone. This resulted in her going up to the Hospital to find out what was going on. We were assured it wouldn't happen again as I was on heat-treated Factor VIII and this was the second infection in our family. I can't tell you what

my parents said and did about it, but they were just destroyed by it. Of course, I can tell you my parents fully participated in the legal cases against the NHS and Armour Pharmaceutical company that took place after these blood product infection events!

28. My Mother also feels heavily responsible for the fact that she was plumbing me with this product. It's likely that she's injected it into me thinking it was safe. It was difficult for my parents to explain to me.

29. I don't know whether the heat treating wasn't done correctly or it didn't work correctly when I was infected. There is no possibility of me being infected any other way. I was a child! I was of course not sexually active or any kind of illegal drug user! It has been well established within my medical records, and it is known where the infection came from. I was infected by NHS repeated use of contaminated Armour Factor VIII blood products, during treatment for my haemophilia!

30. I was infected with HIV, Hepatitis B and Hepatitis C.

31. I naturally cleared Hepatitis B when I was very young (I was at Birmingham Children's Hospital at the time) and I naturally cleared Hepatitis C when I was about 18 or 19 years old. I haven't had particular liver damage from Hepatitis C. However, I have suffered a B cell lymphoma cancer, believed to be related to this infection!

32. I believe it's likely my parents were told everything they needed to know about HIV, Hepatitis B and Hepatitis C by the Birmingham Children's Hospital once I had been infected! I was not old enough to be included in their discussions. I'm assuming this because I do still have goodwill towards the Haemophilia Unit. I do not believe my infection was the fault of the staff directly working on the unit! I know it was the use of contaminated products that was to blame! Not the staff!

33. However it was well known that the seats, table and toy boxes were covered in cling film by the Hospital as they had little knowledge at that time about how these infections could be passed on. You can imagine this was also distressing for my family!

34. Once I started getting a little older, my parents told me in stages, which initially started with 'You've got something in your blood which means other people can't touch your blood'. And I needed to be extremely careful when playing with my friends!

35. My parents then told me that I needed to be extremely careful in PE and accidents. I wouldn't take part in some of the physical activities in part due to the bleeding disorder, but I realised in later years this was also because they didn't want me to infect other people, such as the other children at my school!

36. I would have been aged 14-16 when I found out about all three viruses through my parents. They also told me why I needed to be careful around girlfriends. Yet at this point, I still did not fully understand the consequences. The full explanations came later on.

37. By the time I transferred to the Queen Elizabeth Hospital, I received a proper education about HIV and Hepatitis and what it could do. I was told that it was much easier to transmit Hepatitis C through body fluids than HIV. HIV is actually less likely to be transmitted to another person than Hepatitis C.

38. However it must also be stated with each of these viruses that it is still possible to infect someone with a single exposure! I now know it is highly likely that when we were infected, we were exposed to multiple viruses, through the batches of Factor VIII many times - each injection of contaminated Factor VIII within an infected batch (each batch being used many times) adding the likelihood of us becoming infected!

39. The Queen Elizabeth Hospital were also very helpful in telling us what to do in relation to sexual partners. They told us about taking precautions, the potential risks and making sure that we were extremely careful if we did get a Partner. They never discouraged us from getting a Partner or having a sexual relationship with a Partner. In fact, they were very supportive. However, they were all also very forthcoming with the potential risks and the need to take as many proper precautions as possible!

40. I myself needed to be counselled by the Queen Elizabeth hospital staff and my social worker working at the Queen Elizabeth Hospital, when I met my first girlfriend, now wife. I was desperately afraid of what harm I could cause her as I was infected!

41. Both the Queen Elizabeth hospital haemophilia unit staff and my social worker have been very supportive and extremely helpful regarding my fears surrounding my infection and a potential Partner! They have always advocated that we need to be very careful and take proper precautions with our Partners!

Section 3. Other Infections

42. I was infected with HIV, Hepatitis B and Hepatitis C. As explained earlier, I naturally cleared Hepatitis B and Hepatitis C.

43. I have however suffered very significant, short and long-term damage to my health, due to the HIV and Hepatitis C infections including B cell lymphoma cancer, which I am now currently clear of! This damage to my health is ongoing!

Section 4. Consent

44. My parents would have agreed to me being tested for HIV and Hepatitis, purely because of my cousin having been already infected by the contaminated blood products.

45. I believe that any other testing or treatment on me would have been done with my parent's consent.

46. However, as previously stated, my parents would have had very little choice, given the nature of my haemophilia bleeds, causing me extraordinary pain! This would have been deeply distressing to watch! And of course, the bleeding episodes could have been life threatening to me!

47. This fact is also why the NHS's responsibility to deliver clean and safe products was so incredibly important! The NHS and Department of Health neglected and ignored this responsibility, condemning us all to a variety of known to be lethal infections!

Section 5. Impact

Cousin

48. My cousin passed away when he was 12 years old, in 1992. We were both the same age. He died of double pneumonia directly related to the HIV virus. At that time, everything he had gone through, regarding our shared haemophilia I understood, and I was the only one who could. We were very close. At the point when he was going to die, they brought me to him and I stayed with him for a while. I have had open wounds over this for a long time.

49. My parents told me the exact reasons he died (relating to the HIV) when I was a little older, when they told me about my own HIV and Hepatitis C infections! Obviously I found this even more disturbing than before I knew why he died!

Mental effects

50. Initially you can't really understand what you are being told - that it's a deadly virus and that it's killed millions. You are so disturbed, damaged and impaired by your other illnesses that you just treat it as another illness.

51. Unless you have been desperately ill with illnesses related to the viruses, and needed to be treated to save your life, or been educated about the precautions you have to take, you don't even understand the implications of having an infection. Even general conversations and TV programs didn't teach you about the many ways it can be dangerous and its effects.

52. However as soon as my understanding of the infection became clearer, I began building mental walls. I thought I was dangerous. How do you behave if you know that you're dangerous? How can I have any sort of Partner? Ultimately you know this thing is a killing machine which makes you a danger to anyone.

53. I eventually had a mental breakdown at the age of 17 because of the implications of meeting a girl. My brain couldn't deal with it because I'd built so many mental walls to protect everybody else. It was more at the point where I was meeting girls, your body just wants to interact normally, but your brain tells you that you're dangerous.

54. Up until the age of 24, I was a very closed off person and stayed in my bedroom - I didn't go out and see people. I was phobic about interacting with anyone because I was damaged. The precautionary tales and the stories that a lot of us were dying also does a lot of damage to your ability to interact with people. I never had a girlfriend until I met my wife around 2005.

Physical effects

55. I used to do voluntary conservation work where you use billhooks and axes. If you cut yourself you would do your best to keep people away from you until they're wearing gloves and protective medical equipment. Everyone wants to help you if you cut yourself, but you have to be the cautious one.

56. Once, while working there, I cut my hand while working. I remember kicking the medical guy away from me because he didn't know I was HIV positive. I had told their office, but apparently he did not know! He kept trying to help me! I had to stop him because I could endanger him as he wasn't wearing the right equipment. Once I informed the medical guy that I was HIV positive, he put on the proper safety equipment and then allowed me to treat the wound myself!

57. But the whole experience only illustrated my fears around my being infected with these viruses, and that fact making me such a potential danger to others!

58. That experience only reinforced my fears that I'm always going to be a potential danger to those around me, no matter what I do!

59. You are seriously fatigued all the time because of the viruses. You're constantly on drugs which are referred to as similar in side effects to a low form of chemotherapy! The virus treating drugs make you always nauseous, sick and tired. You're toxifying yourself with the pills every single day just to stay alive!

60. Everything I've ever tried to do goes wrong because of my illnesses. The effects of the viruses, and even when it is suppressing my HIV virus the side-effects of the treatment for it, coupled with my haemophilia, makes doing anything extremely difficult. Any kind of physically challenging thing has been completely destroyed in my case.

61. I literally don't go out at all because I'm trying to preserve my health. You know you can't do that activity as you know where it will end up! You will either end up ill or you will injure yourself. So many different things are in the way. You don't get time to have any kind of normal life. This always puts mental and physical blockades in your way. Most are blockades you can't get past! So I always feel trapped! Whatever I do, wherever I try to go, the viruses are coming with me! This means there is never any way to escape their effects! This is deeply demoralising as well as incapacitating! It makes you feel as if there's no point trying to do anything!

Further medical complications or conditions

62. You never stop having infections and odd un-diagnosable things. They tell you that they can't diagnose things because they're so strange, which then means that they can't treat you. The principle in the NHS, rightly or wrongly, is that 'If I can't diagnose it, I can't treat it'.

63. I've had 10 particularly bad infections that have hospitalised me. The policy is always not to give you antibiotics until they can isolate what it is. You just have to stay in bed and hope to get through it.

64. In July 2005, I was diagnosed with B cell lymphoma cancer in my chest. It was the size of a large orange and a direct result of the Hepatitis C and HIV viruses. That's all on record and resulted in Skipton stage 2 payments, which I will talk about later.

65. I started treatment straight away and I was clear by January 2006. I was supposed to have six courses of chemotherapy; however I only managed five courses due to suffering serious illness, due to the side-effects of the chemotherapy and my severely weakened immune system. During the last four courses, I had to be given injections to boost my white blood cells, before the hospital was allowed to administer each course of chemotherapy. By the time I reached the sixth course of chemotherapy I

was too ill to receive it. Though I should have had this sixth course, I couldn't tolerate it. I was told that if I had received the final course of chemotherapy it would likely kill me. So this could not be done! Fortunately, the fifth course was enough to kill the cancer!

HIV Treatment

66. As soon as I transferred to the Queen Elizabeth Hospital, they started treating the HIV straightaway as apparently my viral load was through the ceiling and they had a different policy to the Birmingham Children's Hospital. This was around 1997, when I was 17.

67. HIV is treated in tablet form all the time and you're never off the drugs. The goal of the HIV drugs is to suppress the viral load, which is the amount of virus in your blood that never actually goes away.

68. There are several groups of HIV drugs and you need to be on tablets from at least three groups to fight the virus all the time. I am currently on a triple therapy treatment. However, with the current method of treatment, the biggest problem I have is that as soon as I become resistant to one drug, it is necessary to change it.

69. Currently I am resistant to two groups of potential HIV drug treatments and half from another group. This means those drugs will no longer work for me. They no longer suppress my HIV virus, and therefore can no longer be used - that means my options are gradually running out.

70. The drugs make it incredibly difficult for you to eat. Your appetite has been destroyed so much that you don't put weight on properly which makes you more susceptible to picking things up. I was very thin, very unhealthy, very gaunt, very lethargic and not having the best time in the world. In recent years I've been putting more weight on and looking better in myself. The drugs also cause muscle fatigue and mental tiredness.

71. There was a period when I was unable to take the HIV tablets so I came off them for a while. This was around the year 2000. I was off treatment for my HIV for around five years because of the side-effects of taking the HIV pills being so unbearable.

72. Despite what the HIV virus was doing to me when I was off treatment, I actually still felt much healthier at that time. I think I just lost the will to keep going with the treatments because the side-effects were so rough! I knew I'd likely die off treatment, but honestly I stopped caring, because I felt so ill with the side-effects!

73. However, in 2005 and just before I was diagnosed with cancer, I went back on HIV treatment due to meeting my first girlfriend, now wife GRO-B and my obvious need to keep her safe! It obviously became necessary to force my HIV virus back to being undetectable, so that I was less of a risk to my wife!

74. However, during restarting my triple therapy HIV drugs, I became very ill and was suffering major migraines. I was bedridden and unable to move due to a serious form of headache. I ended up in hospital and I was found to be allergic to one of the new drugs I'd been put on to combat my HIV - Efavirenz. I am no longer able to take that drug.

75. This illustrates how significant the side-effects of triple therapy drugs can be. They are very difficult drugs to tolerate and their side effects can be truly terrible!

Medical and dental care for other conditions

76. The dentists are afraid to do anything with you due to the bleeding disorder as well as the HIV status.

77. Even when they see you, they won't do a lot with you. They would wear two sets of surgical gloves as a precaution and you're always treated last in the day with a specific set of equipment for the HIV positive patients.

78. My teeth are a mess now with several needing to be extracted. However getting them to do the extractions is hard because they're afraid of you bleeding and of you being a risk. I had to have one tooth extraction at the Queen Elizabeth Hospital and they had to take me to the theatre for that. We can't be treated through normal means because no-one is qualified normally to handle that many issues at once.

79. In my late teens, I had pancreatitis five times and the Doctors thought it was related to the HIV. They told me I should have been dead after the third time. My mother always feared, and expected me to die during these periods of illness, and also during several serious chest infections that hospitalised me, due to my compromised immune system which was HIV related!

80. I suppose it's always been reasonable for my family to fear I would not make it this far, considering the death of my cousin C when we were both 12 years old, due to these same contaminated blood product viruses!

81. With my GP, the only thing I've ever been able to get treated have been very mild things, such as a rash. Even then the conversation is 'Have you consulted with your main team?' First and foremost, the haemophilia is the main concern even next to the HIV. The GP has no way of understanding all of the implications of all of my illnesses, particularly the potentially complicated effects of my HIV, especially when complicated further by my haemophilia infections, leading to internal bleeding, for example! I've got a GP, but he can only be used to treat very insignificant things.

Private, family and social life

82. I have had to live life like a hermit in an odd way of self-protection. I don't have friends. When I did, I caused them problems because there's so

much involved in my care. I'm really hard to deal with in the sense of getting to lead a normal life. Every time I've tried, I've ended up in hospital.

83. For example, I used to have a group of friends who I met on Thursdays. We went to the Glastonbury Festival together. However two days into this event, I developed a serious knee bleed despite being on Factor VIII treatment at the time. I had to be taken by a makeshift Land Rover ambulance to the nearest hospital, leaving my friends to have to pack away and take home all of my gear. I was hospitalised for a week and a half and spent a month in bed.

84. My efforts to include myself, and participate like a normal person with friends, just made me a burden to them! As usual, I just ended up injuring myself and causing my friends awkward problems! As has so often been the case, simply for trying to be there with them, I effectively ruined the end of their trip.

85. Thanks to problems caused by my multiple illnesses, I have repeatedly found myself being a burden and nuisance, in ways like this, to any friends I used to have because of issues like this. I don't interact with any friends anymore.

86. On another occasion, when I was in my early teens, myself and my immediate family had backstage passes to another event, which I was desperately looking forward to. However the day before the event, I was hospitalised for a fortnight with a serious chest infection associated with my HIV. Once more, my family had to cancel the trip and lost what they had paid - again, the illnesses sabotaging everything I try to do, and costing my family!

87. These days, I don't leave the house without my wife GRO-B She's taken on trying to get me out. It's very rare but she's getting me to interact more too. She has been a Godsend to me because she's a qualified support nurse and phlebotomist, and since she's always worked in either heavily

disabled, mental health care homes or NHS hospitals, from wards to A&Es. GRO-B has always proven herself to be capable of not just being my wife, but also being capable of being a nurse to me when I'm hit with the illnesses these viruses have led to, such as my lymphoma cancer!

88. This is the kind of thing our partners need to be capable of, to handle the complexities of our compromised health. This is why finding a partner is so difficult for us. And also why my wife is so precious to me!

89. When we go out, we only really go on short direct trips to the bank or the shopping centre. If you go shopping and you get things, it's great. However, whatever you do mechanically, you end up paying for it by injuring yourself, so it's not really worth it. So I only do this when it's absolutely necessary.

90. We recently went to Cheddar Gorge in Somerset. This was our first time out in four or five years. However I was heavily restricted and the trip was curtailed because I'm not mobile. We couldn't go inside the actual caves, I was just rolling up and down the road in my mobility scooter. However, this was much more than I could previously do, over the past few years. In recent years, because of my mobility declining so much, any attempts to go out became too painful and difficult, keeping me almost totally housebound. This was before I recently got my mobility scooter.

91. In terms of my parents, I do not have a relationship with my father anymore. He started drinking and becoming violent. My father's reasons for being violent were mainly alcohol-related but otherwise there was never any clear reasoning from him about it. Although, throughout the years, I did pick up that my father was resenting the fact that I was too ill to work but a little more financially stable, while he himself continued to have to work as a manual labourer. This seemed to frustrate him in his later drinking years, and seemed to fuel his aggression towards me, and my mother for defending me.

92. I was more stable because of the sums of money awarded to me from the UK NHS infected blood product litigation settlement in 1991, and the US Armour Pharmaceuticals litigation settlement in 1992, though at this time my payments were locked away from me until I was an adult (not allowing me to help my parents at that time). In later years, this created friction within my family as although this settlement money was not enough to support our family, it was more money than my family had ever seen, because they were always relatively poor.

93. And my family was certainly not well supported by any of the charitable payment systems supposed to support us after we were infected, such as the Macfarlane Trust (MFT). My parents did not benefit from any grant support from this organisation right up until my former social worker's intervention when I was 17. Before this, my parents were not informed the grant support was supposed to be available to them, for my care. My mother has since stated that anything they were aware of regarding grants support, was made far too difficult to apply for, and impossible to get from those organisations!

94. My father had written many statements for both contaminated blood products litigation cases, as I, myself, was a child at the relevant time. He (including my mother) also wrote to Peter Snape Esq MP about the HIV Haemophilia litigation before it was settled. His letter was passed onto Virginia Bottomley, former Minister for Health, who replied in a letter dated 16 November 1990 (**WITN0008003**).

95. Due to all the work that my father did, he treated me like I owed him. He resented the fact that I was getting a financial benefit due to my infection. He sometimes used the fact that I was disabled, had been infected, and therefore was unable to work and on benefits, as an excuse for his overly aggressive behaviour. At that time, I was no longer being financially supported by my father. But he seemed to resent having to support me in my younger years.

96. During his drunken, aggressive and sometimes violent outbursts, my father used my disability and illness as a verbal weapon as one of the reasons, or as an excuse, as to why I was deserving of what he was doing to me, and my mother. Though it is true that my father never really needed a reason when he was drunk and being abusive.

97. During this time, my sister left home, directly because of my father's aggressive behaviour towards us, which also occasionally included aggressive outbursts directed at my sister.

98. My mother and father ended up getting a divorce and I bought him out of the house to finalise it, to prevent him physically harming us any further. This has left me with a complicated relationship with my mother because some of my infected blood product settlement money is wrapped up in her house. She also became somewhat dependent on my financial support.

99. During the time, I lived with my mother because of my infected status. My MFT payments, though still woefully small at that time, did still allow me to help my mother afford to maintain a slightly better standard of living than my mother could have afforded by herself. Of course, when I was able to, I was happy to help my mother in this way as at the time, we lived together and we had a good relationship. Until more recent years, we usually got on happily and well.

100. I do feel it's essential that I put on record that throughout my younger years, my mother, GRO-B was always remarkably supportive of me, both in normal ways and in caring for my compromised medical health! My relationship with my mother was not always so difficult! In fact, throughout most of my youth, my mother was the best mother you could have asked for!

101. I needed to leave the family home when I met my wife in 2005, when I was 25. My mother didn't know how to deal with this as she lost a hold of what she must have grown to feel was indirectly hers, and should be used

to also support her. The financial security of the money became a real, irreparable, relationship breaking obstacle, between myself and my mother, when I met my wife GRO-B My mother found it impossible to allow me to move forward to a relationship with my wife, as she feared this would compromise her own security.

102. Note, I'm putting these financial difficulty issues on record within my statement for the inquiry into infected blood, as I'm hoping the Inquiry will recognise that the woefully low forms of payments (compensation, not compensation) issued to beneficiaries of the infected blood charity trusts has usually been far too low to eliminate our difficulties, in both our compromised health needs and quality of life. This is because the financial support provided has always been such small figures. As a result, it has often caused as many problems as it has helped us resolve, within our irreparably damaged lives! That is if we can get the trusts to pay out at all!

103. I met my wife shortly before I was diagnosed with cancer in 2005 - we moved in together and were living together in a flat. This is thanks largely to the help of my social worker at that time, Mark Simmons, who was Queen Elizabeth hospital based! My then social worker Mark, heavily supported us through this difficult transition period. However due to my cancer, I had to move back to my mother's house, as asking my wife to handle this alone after we had only just met seemed like it would put too much pressure on our relationship, at that early stage!

104. After recovery from the B cell lymphoma cancer, I moved out again. My mother became resentful of my wife as if my personal problems within my relationship with my mother were all my wife's fault. As if it were my wife's fault that I needed to become more independent and move on with my life!

105. She unfairly and wrongly grew to blame my wife for me no longer getting along with her, my mother. And therefore we were no longer able to co-exist under the same roof at my mother's house. The personal and financial complications made this impossible!

106. My mother obviously felt my marriage would damage her own financial security. And my mother also wrongly worried that she would lose her own home as some of my settlement money is still trapped within it. And I was now moving on! My mother doesn't understand I would never threaten her own security in any way! I have only ever wanted her to feel safe!

107. However my mother's feelings were not always hostile to me being in a relationship! Throughout my childhood, my mother was remarkably supportive of me growing up and meeting someone. She was always telling me that it's not about my mother getting anything, it was about setting up my future. Somewhere along the way, she disproved what she told me she believed, which I found difficult.

108. It is due to the financial complications that I don't interact with my parents anymore. My parents seem to think that my personal and financial future ought to be directly under their control, since they had sacrificed so much to support me in my earlier years of ill health! Some of this I understand. But as I became an adult I could no longer continue dealing with that kind of pressure, on top of all my health pressures!

109. Even my sister didn't know how to interact with me when the money came into my hands. She would think that "I don't want to ask my brother for anything" even though I would happily help her.

110. The money has been a major problem with my family because they are quite poor. Though all the payments I received from the settlements, trusts and disability benefits are not sufficient to make up for the damage that was done to me, when I was infected by the NHS purchase infected blood products, it is however much more than my family could ever earn themselves, through work or if they were on benefits. It was difficult for my family to see me with all this money because I didn't do anything with it and I didn't really initially spend anything either - even after it was released to me after I turned 18! And the bonds the settlements were locked away in, matured!

111. I have always been so badly broken by my illnesses, that there is nothing I could possibly buy with the money I had, that could help me in any way! Medically or socially! Practically speaking, the funds I do now receive, barely stabilise my quality of life! And the Macfarlane Trust payments didn't help at all in previous years, when the payment figures were so much lower and were not enough to help fix anything. Now the money just sits there as a cushion for unexpected problems, as I'm always fearing the worst, when it comes to health, because of my compromised immune system!

112. It's difficult to know how to use the money to stabilise my declining health and well-being. I simply don't know what this money could do to help me! The money is a constant obstacle and caused the breakdown of interaction with my family and the outside world.

113. When everything about your health is so badly damaged, and even your basic human rights of having children and starting a family of your own are destroyed, by being infected in this way, the money does not help you live a more normal life! Because even if I did have children, they would either be infected, making me seem like a villain! Or even if they were not infected, my declining health would still make me a burden to my children! And this would create an even bigger burden for my wife, than she already deals with!

114. When everything you could have done that means anything, and everything you have a right to be, is taken away from you, the money is useless, but it is also all that's left! It's hard to call it a help because I don't think it really does, but without it we'd be a real mess. It's needed but it is more trouble than it's worth.

115. I don't have any children. My child, not only could have haemophilia, but could also carry and have to suffer the viruses, and would still have to deal with a Father that's a complete mess! A broken diseased thing! That's no life for any child. I just would never want to put any child through that. You

can understand how I would construct barriers when that's the life you've got.

116. Obviously that also makes my wife's relationship with me pretty categorical about what route we can go down. I come as a very complicated package that she just has to deal with. It even affects how intimate you are. We're just not because it's too complicated and potentially risky. It is one of the most valuable things to most people, but became for me needing to be treated as off-limits, needing to be looked at as an unacceptable, dangerous risk to my wife, in my relationship with her!

117. Imagine for a moment knowing that just you and your partner loving each other, in the most natural way possible, can kill your partner! That overbearing threat, makes that side of your relationship impossible!

118. With my education, every attempt has been broken by the viruses, haemophilia, bleeding disorder and brain haemorrhage-caused epilepsy. My experience has been that you can do a one-off thing, so long as you accept the physically damaging consequences! But if you try to do several days or weeks of a thing, by the third week of trying, it will implode because of illness events. It meant that I was at school 75% of the time at best, and always behind. But post brain haemorrhage I was slow anyway.

119. Both illnesses due to my HIV and my epilepsy, destroyed my final school education. Through ill-health caused by all my variety of illnesses, including the viruses and associated sickness, I missed a lot of school. Throughout my school years, I also had to spend my last year at home being home-educated. I missed all the school exams because I was again very ill, with something related to HIV, and once more had to spend that period in hospital!

120. I attended college but they had me painting pine cones, which they called 'creative art' because I was never going to do anything in the working world. I found out there that they seemed to put anyone with little to no working prospects in these going nowhere, pointless courses! I failed to complete that course because I was having so many bleeds and other sicknesses, which meant I was barely ever able to be there. Though this did seem to be a waste of everybody's time anyway!

Stigma

121. I didn't suffer from stigma as much as most. I had a supportive school but you still can't go out and talk about it normally with people because they don't know how to react. Even when you don't get the 'Where did you get that from' kind of people, they'll try to be sympathetic when you're just trying to teach them why you can't do a certain thing. People like your friends don't want HIV landed in their lap so that they have to empathise with it. They couldn't know how to anyway! But my school was as supportive as they could be, allowing me not to do potentially dangerous lessons such as woodwork and PE. I did find this frustrating, but I understand it was necessary!

122. I have always been good at dealing with stigma by knowing it is there but not being particularly hurt by it, because it doesn't do you any good. Gradually through the years, the less it's on TV, the less worried the outside world gets, but when you're in the middle of dealing with it, the stigma is secondary. The damage the viruses are actually doing to you will always have more impact on you over any potential stigma!

123. Though, it has to be recognised that throughout the years, the media perception of the viruses has been very damaging. We all remember the infamous HIV ad campaign that worried or frightened everyone who saw it! Though I was young at the time, it's obvious that that campaign made it very difficult for anyone who was HIV positive!

124. I also remember that when Freddie Mercury died due to the AIDS virus, this was deeply disturbing to my parents! It was a few years later that they really explained to me why this had upset them so much! Obviously it only magnified the implications of my own infection with HIV!

125. Obviously, when my cousin C who was also a haemophiliac, and was also infected, suddenly became very ill with HIV related double pneumonia, and died very soon after in 1992 when we were both just 12, it was this event that damaged my family the most. No stigma will ever compare to the damage this did, both to my aunt and my own immediate family. After this happened, my parents, of course, could only expect that I would die at any time soon after! It's not possible to live a normal life after that, especially after I lost the closest thing I had to a brother, who understood everything I was going through!

126. The real events, and implications of the viruses are far more hostile than people's stigma! These days, if anything, they over-pretty it now. They try to tell you, you can be as normal as possible when there's no real chance of that. They tell you if you get a Partner, you can still be active with precautions. They don't tell you about the dangers of things like condoms splitting! They just try to be overly supportive.

127. I find myself hitting my mental barriers because I know better. I've experienced that normal life can't happen. Every time I've tried to be normal, it goes wrong in some medical way or another. I just have to exist with this thing and try to stop it hurting everybody else. That is from direct experience of things going wrong.

Section 6. Treatment/Care/Support

128. In terms of the treatment, care and support, I was helped by my haemophilia unit based social worker and I had most of my medical care handled by the Queen Elizabeth Haemophilia Unit, which also included a home visit from the haemophilia unit community nurse visiting me,

reasonably regularly. The nurse would report issues to do with my haemophilia and HIV to my haemophilia unit, where I was also treated for both my haemophilia and my blood product related infections, at that time.

129. At present, both of these medical and social support positions have currently been taken away from the haemophilia unit, due to financial and staffing issues. I no longer benefit from this kind of support, though it is still desperately needed to support my health, well-being and social needs! Removing this support, has made things very difficult for me!

130. Having both was particularly important to me and my family when I had a mental breakdown in my late teenage years. Both the social worker and the community nurse were essential to me recovering at that time.

131. As for counselling, I don't recall that ever being offered but I wouldn't swear by it. It may have been available at the Queen Elizabeth Hospital but I wasn't in a condition for it to have helped me. It's likely that I would have refused it because I find it counterproductive - it just draws it up to the surface and antagonises more than it would help. However, I am sure that victims with a different personality to mine would have benefited from any counselling service offered and provided! I am just not the type it helps! I am sure a counselling service would have been desperately important to some victims, if it were available!

132. However I read in one of my parents' letters to Peter Snape Esq MP dated 14 November 1986 that there was no counselling service at the Birmingham Children's Hospital or the Queen Elizabeth Hospital (**WITN0008004**). Their letter was responded to by Baroness Trumpington in two letters dated 9 January 1987 (**WITN0008005**) and 10 March 1987 (**WITN0008006**, in which she talks about funding for counselling.

Difficulties accessing HIV treatment

133. At the Queen Elizabeth Hospital in Birmingham, the change to treating our HIV and Hepatitis C at the G.U. clinic (HIV department) instead of on the haemophilia unit, has caused some complications. This is because their policies are very different to that of the Haemophilia Unit - this ended up causing me a number of medical problems.

134. Previously, my HIV treatment was handled by my consultant on the haemophilia unit who was qualified to treat my haemophilia, and was also qualified to treat my HIV and Hepatitis C needs! Recently however, our HIV and Hepatitis C treatment care was transferred to the G.U. clinic, away from the haemophilia unit. This transfer appears only to have been implemented to provide this HIV and Hepatitis C treatment service as cheaply as possible!

135. I do not want to be treated for any illness as cheaply as possible, as this attitude within the NHS is what led to our being infected in the first place!

136. During the change to the G.U. unit, I was put under the care of a number of new consultants who were not familiar with me or my case, which due to differences in policy compared to the haemophilia unit led to changes to my HIV treatment drug regime. This in turn led to me suffering many new side effects, some of which were extremely painful and well beyond a level of illness I could tolerate! I've since had to take more control over my HIV treatment regime myself, and I have had to revert many of my drugs back to what I used to take and tolerate better.

137. The G.U. unit only seem to want to change the drugs to newer or more cost-effective versions! It doesn't seem to matter how negatively they affected me! But I don't need to be having to deal with bombardments of new-side effects, just to make things more routine for the G.U. clinic! Therefore we've had wars with the G.U. clinic to make them leave things

alone in relation to the HIV drugs. I am currently still having to force them to leave my HIV drug regime treatment alone!

138. However, in contrast, when my HIV treatment medication was arranged from the haemophilia unit in conjunction with them, this worked much better in understanding my complicated treatment needs! Knowing me as effectively a lifelong patient helped the haemophilia unit customise my HIV treatment specifically to my multi-health problem needs! Changing to the new system has made things much more difficult for us all as patients!

139. I do want to put it on record that the treatment I received, when I suffered my B cell lymphoma cancer in 2005-2006, could not have been better! It was clear at that time, the treatment I was receiving, was being delivered as expertly as was humanly possible! I'm quite sure this level of expertise was a huge contribution to my surviving that cancer!

140. However, over the years I have suffered some problems getting treatment relating to illness suffered via HIV-related opportunistic infections, which hospitalised me on a number of occasions! On these occasions, while suffering from these opportunistic infections, I needed to be hospitalised as I was very ill! But once in hospital, I found myself receiving no treatment whatsoever due to the NHS hospital's policy being that if your illness cannot be diagnosed, the doctors will not administer any treatment! As previously stated in this statement, the hospital's view is if they cannot diagnose it, they will not treat it - leaving whether you recover, down to chance!

141. This lack of treatment has in the past led to me having to sign myself out of the hospital because I was receiving no treatment there! At that point it seemed obvious to me that I would receive better care, going back home to my family, despite being desperately ill! Obviously I was disgusted with this at the time. And this has happened more than once!

142. Other than this, and a few small problems with the Queen Elizabeth hospital dental department and the old Queen Elizabeth hospital pharmacy, I have not had any other problems accessing treatment.

Section 7. Financial Assistance

NHS infected blood product settlements

Original government settlement

143. With my parents acting on my behalf, because I was a child at the time, I was involved in the original infected blood products litigation against the government - Department of Health and the NHS. I did receive a settlement along with everyone else who had also been infected. My also infected cousin, C will also have received the same settlement as me!

144. However, I've raised this because I believe the amount children received from this settlement was orchestrated to be unfair! This is because any victims who were children when they were infected, got a much lower figure than adult victims and adult victims with children.

145. As infected children at that time, I believe my cousin and I only received £20,000 from this settlement. Whereas, I believe, infected adults would receive, £40,000, though I'm unsure if they needed to be married to receive this! And I believe, infected adults with children would receive £60,000. As I said, I believe this to be terribly unfair!

146. The settlement amount levels deliberately did not take into account the fact that all children who were victims, would eventually grow up to have a right to raise a family of their own! And therefore, us child infected victims should have had an equal right to receive the same level of settlement as adult infected victims! This was another occasion where I believe my cousin C and I were deeply mistreated! And I believe, myself and

(since C has died) C mother, GRO-B have a right to feel cheated by the authorities regarding this settlement's clear, age-based discrimination!

American settlement, against the Armour pharmaceutical company

147. I was also involved in the American litigation against the Armour Pharmaceutical company. Again, I was a child when this was done, so I'm not certain of the details! Though I do still hold documents from this litigation. I do know, my parents again acted on my behalf because I was a child at that time!

148. I believe I was only included in this litigation because my medical records showed negative results for HIV and Hepatitis C infection before the end of 1986, then my medical records showed positive results for the viruses after this late 1986 date, and after being treated with certain batches of Armour Factor VIII products! The legal documents I hold regarding this case contain full record of the batch numbers of Armour products I was treated with at that time! I believe only 10 other infected victims were allowed to be involved in this American litigation! This litigation resulted in my receiving a second settlement, which amounted to, I believe £60,000, in my case.

149. Both settlement amounts were locked away in a bank account until I reached the age of 18. As this action was recommended to my parents by financial advisers, I believe this was also done in the case of my cousin C and his original settlement amount. This was despite the fact that both myself and my cousin C were expected only to survive, at that time, for a period of 5 years after our infection!

150. In my cousin C case, because his original settlement was also locked away until he would turn 18, and because he died when he was 12 years old in 1992, he would not have received the benefit of the original settlement. I have always found this deeply troubling and unfair on him!

151. I have included this American settlement information in my statement, as this was another example of my cousin C and many others, being excluded, from receiving access to this potential compensation.

152. Though, I must also point out, I don't believe the amount I received even remotely makes up for the fact that my infections, like everyone else's, have devastated my life. And as infected victims, our ongoing infected status is expected to cause our deaths!

MacFarlane Trust, and EIBSS, regarding my cousin, C and his mother.

153. I must first state that upon my cousin's, C death in 1992, aged just 12, directly due to his HIV infection, C mother, GRO-B will have been almost immediately and completely cut off from all MFT support, by the MacFarlane trust itself! As it was, and still is, the MacFarlane Trust's policy is to stop all payments made in a primary beneficiary's name, a short few months after their death.

154. This means, my aunt, GRO-B was left grieving her son's death with no form of continuing financial support via the MacFarlane trust or EIBSS, from 1992 onwards to present day - leaving her with nothing but pain and grief! This is obviously horrifically unfair!

155. I do believe a small, one-off payment is made to the infected victim's bereaved next of kin. But it is so small in amount, it will have done nothing at the time, to help my aunt through her devastation.

156. This one-off payment from the MacFarlane Trust also does not provide any ongoing support in financial assistance to my aunt and other bereaved victims, which if support were provided, would in some small terms provide bereaved victims some stability, while they deal with their

extraordinary loss! This great loss being in emotional, physical, mental and financial terms.

157. None of the current or past schemes have ever compensated groups like infected victims' bereaved parents in any significant way. I believe this to be extraordinarily unfair - adding huge amounts of further damage in neglect, grief and further insult to the surviving, already grief stricken, family members of the extremely large number of infected victims, who have died.

158. It is also extraordinarily unfair that the current Scottish system, SIBSS, has already recognised that bereaved parties do have ongoing needs for support! Meaning, Scottish bereaved victims now receive 75% of the deceased infected beneficiaries' ongoing monthly payments, after the primary infected victim's death.

159. The English system, EIBSS, refusing to recognise and also do this, is not only disgustingly unfair, but discriminates against English bereaved victims in an intolerable way!

160. If it does anything at all, this Inquiry must ensure that whatever resulting actions are taken, as consequence of the Inquiry, and any resulting compensation delivered as result of this Inquiry, or any resulting changes to existing payment systems, must fully and equally include all these bereaved groups! And any resulting compensation payments should also be forcibly back-paid to the date of the primary victim's death! This is to account for these currently unsupported, unfairly treated bereaved victims, and their long-term, traumatic loss with all of its hurtful dimensions!

MacFarlane trust

161. The financial assistance through the MacFarlane Trust has never been enough for anyone to cope. As I said previously, because it is such low figures, it can often cause more problems than the payments can solve!

162. Also one of the main problems with the Trust has been that as soon as you die, the MacFarlane Trust cuts off your next of kin so the primary beneficiary's payments are stopped soon after your death! And then, despite your next-of-kin's devastation to their lives and financial security caused by your death, our family do not receive any regular payments in your name.

163. I do believe there is a small, one-off payment available to the bereaved next-of-kin. But this does nothing to support them through this obviously devastating emotional, physical and financial loss!

164. The MacFarlane trust and Skipton fund in my case, have been an endless torment. And I know this to be the case for a great many infected blood product disaster victims! As a former attender of the MacFarlane Trust's Partnership Group, who went to their meetings, I myself heard many complaints from many victims regarding the trust's horribly unfair treatment, policies and methods! Unfortunately, much of this has not changed with the change to the new organisation, EIBSS!

Regular payments

165. The MacFarlane trust, while it existed, made set amounts of payments which increased over the years. Just before the Archer Inquiry, it equated to around £7000 in my case - though how much you could receive depended on any other income you received, which would have to be annually submitted by the beneficiary, and then would be somewhat spitefully scrutinised by the MacFarlane trust, reducing payments to any beneficiary, with a higher unrelated income.

166. These annual payments would then be supplemented by small grants available through the MFT - so long as you had been informed these grants existed and you yourself knew how to apply for them. However I

had not been informed of their existence until I was 17, and therefore did not get any grants until I was that age.

167. In later years, even Skipton regular payments would be used to reduce the level of the MacFarlane trust payment you received. Obviously this was woefully unfair as you should be entitled to both payments if you'd been infected by both HIV and Hepatitis C. This kind of thing was typical of the unfairness the MFT was regularly capable of!

168. I do have some records from the early years of the MacFarlane trust, which appeared to show that initially payments were much lower than this! But since I was a child at this time and my payments were locked away from me until I was 18, I myself am unsure what amounts were received in the early years via the MacFarlane Trust payments. I also do not know if regular payments were even available in those early years, or if potential support was only grant system based.

169. The Lord Archer Inquiry then happened. And in response to that, MFET was set up as an offshoot of the MacFarlane Trust to deliver a guaranteed, fairer automatic, regular payment system.

170. This was intended to stop us beneficiaries having to beg the trust for grants and payments, and stop us having to jump through hoops to get the support we were supposed to be receiving!

171. At this point, in response to the Archer Inquiry, the government promised to double the payments we were at that time receiving from the MacFarlane Trust, and deliver them through the new MFET.

172. The MacFarlane Trust recommended that the annual payment should be around £16,200, as this figure added up to double what was provided by the MacFarlane Trust in potential payments and grants to beneficiaries at that time. The government refused this figure and only allowed around

£12,800 per year in MFET payments - this is despite the MacFarlane Trust's own protests at this much lower figure!

173. That was just another example of the government betraying its promises of more adequate and more substantial support to us victims!

174. That figure crept up over the years as MFET payments were linked to and increased in line with what I believe, was the consumer price index. I believe this mechanism is still the case with the new EIBSS payment system!

175. Also at that time, after the Archer Inquiry, in line with the MacFarlane Trust's protest at the government's unfair and low figure of MFET payments, the MacFarlane Trust also began providing a top up payment to lower income beneficiaries - it was designed to bridge the gap to the MacFarlane Trust's own recommended figure.

176. However, this MFT top up payment was much more heavily means tested relating to any other income the beneficiary received - obviously the means testing cutting out wealthier victims of HIV infection from this support.

177. I believe cutting out anyone infected or directly affected is unbelievably unfair! And I believe this discriminates against those victims! Of course your wealth does not stop HIV from ravaging your compromised health! I must state, we were all equally devastated by being infected and were all negatively affected in many ways! All victims of this disaster should be equally entitled to receive whatever support is available!

MFT Grants system

178. During my younger life, my family and I were supposed to be accessing grants from the MacFarlane Trust, but I was not told by the MFT that they existed. I did not receive any grants from the MFT until I was 17 and met

my social worker, who told me about the existence of these grants. He had to teach me how they worked. Mark Simmons, my social worker at the time, told me he had encountered several other MFT beneficiaries who had also never been told about the grants.

179. I believe the Trust did not tell my parents when it started, or at any time after this, that these grants were meant to help my family! My mother has stated she did not know so many forms of grant even existed, or that she was supposed to be able to access them on my behalf!

180. She apparently was not told these grants were supposed to be helping my family support me through my illness. Not knowing what grants were available infuriated my family when they were told, as they could have done with the additional support.

181. At that time, when I was 17, my mother told me when I was younger she did once find out the MFT offered a grant for a washing machine. But when my father applied to get this grant, the MacFarlane trust operated in a way to avoid payment! There were many get-out clauses. I remember my mother told me they made it so difficult that they didn't apply again.

182. I've since learned that this lack of knowing how to access available support from the MacFarlane trust is not uncommon among MFT beneficiaries, as the MacFarlane trust operated in such a secretive way that many beneficiaries were unaware what support was available!

183. It became apparent to me through dealing with the trust that this secretive method was taken advantage of by the MFT to reduce the number of people applying for grants! My social worker has told me he knew many beneficiaries who didn't know what was available to them through the MFT until he had to inform them!

184. I only found out about the grants system around the age of 17 when I was introduced to it by my social worker, Mark Simmonds, at the Queen Elizabeth Hospital. The social worker did the grant applications for me as

I wouldn't understand it otherwise. The trust itself didn't explain anything - my social worker, Mark, had to sort all the grants out for me. Being post-brain haemorrhage, I sometimes found the grant application system procedure very difficult!

185. Initially, during that early period after turning 17 and being transferred to the Queen Elizabeth hospital in Birmingham, and meeting my Queen Elizabeth hospital based social worker Mark Simmons, and once I had my social worker's Mark's help when I first started applying for the grants, it was reasonably straightforward to apply for and get a grant.

186. At that time, actually getting the grant became almost automatic, so long as you abided by the timeframe you were allowed when applying for each grant! Only one grant over a set period of time for each available category! I found this part to be fair!

187. When I moved into my house with my wife in 2006, the MFT grant applications continued at that time to be fairly straightforward! Largely due to my social worker, Mark's vigilance, he even managed to secure for me an additional £7000 grant from the MFT for a disabled wet room, under disabled adaptations grants. This helped me cover the excess cost leftover from a council grant. My social worker Mark, also secured for me for the same ground floor level a disabled wet room which required moving my kitchen to install the wet room! This obviously helped me with my disability and mobility a great deal!

188. For a long time, my social worker would instigate an application and that would be filled in unison with the haemophilia unit. And if they needed medical documents, then that would come through the haemophilia staff via my notes.

189. In terms of the process, it could be insulting and difficult! You are required to send in receipts as proof of spending for every single grant including for things like clothing grants! For example, in the case of clothing grants, a

receipt for every pair of socks needing to be provided by the beneficiary and accounted for, to prove how every penny was spent! This procedure was insulting, and always put unnecessary pressure on us victims! We are treated like some kind of criminal con artist! MFT treated us as if the victim receiving the grant was trying to con the MacFarlane trust, so we could spend the grant money on whatever we wanted! Of course, that was never the case!

190. This MFT perspective has always been appalling! As victims of this disaster, applying for grant support, we were and are to this day treated as if we are attempting to swindle funds from the trust fund, which is supposed to be delivering support to us!

191. Since the new EIBSS scheme still behaves in this way regarding grants, it is clear at no point will we ever be trusted and treated with respect! This mistreatment and mistrust has always been appalling!

192. All us MFT beneficiaries ever wanted as victims of this infected blood disaster was to be able to access whatever support was available, in a fair way, to help us to deal with our damaged lives! Instead, we are always treated with contempt and disdain when trying to get that support!

193. After some time, social workers were banned by the MacFarlane trust from applying on our behalf. As their applications were apparently seen by the MFT as too often successful. This would have been before 2009.

194. After this point, any application could only be made by a beneficiary themselves or had to be applied for by medical professionals, such as your haemophilia consultant on your behalf. That made it harder for my haemophilia unit at the Queen Elizabeth hospital as from then on, they had to handle our MacFarlane trust grant applications, on top of the huge amount of work involved in our medical care, as well as any required medical information associated with benefits!

195. This has made things impossible for the haemophilia unit and its staff! And this MFT, and now EIBSS, grant process is still crippling the haemophilia unit, to this day!

196. Essentially, you had to be in the middle of it to know about all of these obstructions put in place by the MFT associated with the grants. The grant system is diabolical and it caused us to be ill due to the mental pressure. Even our hospital staff have suffered illness due to the stress of trying to support our applications to these trusts. Dealing with these trusts is impossible! And nothing has changed now that we are dealing with EIBSS!

197. After the Archer Inquiry, the MFT grant amounts were reduced and the MFT added that grants are given 'only in exceptional circumstances', which they didn't explain and refused to define. Both my hospital and I found this very difficult. We also had to provide information on all of our outgoings to qualify for grants, as well as our income. Whereas in previous years, a statement of income was all that was required, and only while submitting the annual census form! This private, personal information would therefore not previously be required when applying for grants.

198. After this deeply intrusive MFT policy change, from that time onwards, it became almost impossible to get the grants. I should also say at that point in time, because I refused to allow the MFT to access to my outgoings (as I believed the MFT had no legal right to that private personal information), the MacFarlane trust point-blank refused to allow any grant application I made during that time, which of course banned me from access to support that as an infected victim I was entitled to receive!

199. Also if you receive any other income of any kind, they would use that as an excuse to get out of paying a grant. They made it so much harder for any type of application after that. This continued right up until EIBSS took over after the MacFarlane trust was closed down! However since EIBSS started, as far as grants go, things have been just as bad!

200. In early 2015, I applied to the MacFarlane Trust for a mobility scooter. Despite this, the mobility equipment grant being the one grant I was most in need of, and me being fully backed in applying by my haemophilia unit staff and social worker, this application ended up being the most difficult experience I've ever had with the MacFarlane trust and EIBSS so far!

201. After the initial application, the Trust first demanded medical letters from my hospital to verify my need for the scooter. Since, as always, I had the full support of my hospital, consultant and other staff, I then supplied these hospital support letters. However the MFT still refused my application, insisting any other organisations such as the Council should pay instead of them!

202. The MFT then refused again as I wouldn't allow them access to my outgoings. Since they never asked for or required outgoings information before, I refused to allow that! I felt this demand was deeply intrusive and none of their business! I also knew that the MacFarlane trust has never had any right to access this private information, and therefore they did not have the right to refuse people based on this information! And so it carried on with more refusals and more unacceptable excuses!

203. In the case of that grant, because I was fully medically backed by my haemophilia unit, I continued fighting to try to get the grant I believed I had a right to! The process built up and took 3 and a half years just to try to get one grant!

204. The MacFarlane Trust refused my grant mobility scooter application and hospital backed requests for grants application reassessment 5 times. Each time they gave me different excuses as to why they won't fund it, despite my application being fully medically verified and supported by the Hospital.

205. Eventually my medical need for the scooter escalated so much I ended up having to buy a scooter myself anyway. Then my social worker and hospital demanded that the MacFarlane trust reimburse me, via a grant,

for this mobility equipment - since I obviously was demonstrating clear medical need for the scooter!

206. The MFT again refused this time saying "They would not fund something that was bought retrospectively." Their view is that "You bought it, so you could obviously already afford it". That of course is not the point being supported! You're supposed to be supported so that you don't need to fund support for these medical needs yourself! Also, that excuse was not true as my social worker applied to get the ball rolling before I purchased the scooter! I had no choice, I had to buy it in the middle of this long grant application as my health declined so much that I could no longer go about my life, day to day, without it.

207. I asked the MacFarlane trust to reassess the application several times and they refused several times. I asked the MFT to review it for the last time in mid-2016, and of course they refused again!

208. Sometime after this, the MacFarlane trust was shut down and replaced by the EIBSS! In June 2018, I applied for the mobility scooter again, this time through the new scheme, EIBSS. This time I requested support for a folding machine I could collapse and put in a car, as by that time, I'd deteriorated to such a degree that I could no longer go anywhere at all without the scooter. EIBSS also gave me six months of refusals! EIBSS were claiming they couldn't understand how anyone would need a mobility scooter relating to their HIV condition, before eventually allowing the grant in late 2018!

209. I will deal with this EIBSS grant application, and further issues with the EIBSS later in this statement.

210. EIBSS eventually accepted and approved the mobility scooter grant application, proving that I'd always had every right to this medical equipment grant! But this goes to prove how difficult these grant applications were made by the MFT, and are still being made by the EIBSS! These organisations put me through hell, just to get one grant.

This makes the grant process impossible to work with, and enough to make anybody very ill!

Skipton

211. In 2005, when the Skipton scheme was introduced, I was put onto Skipton's records as I was also infected with Hepatitis C.

212. I qualified for the stage 1 payment of £20,000. Mark (my social worker) and the hospital processed the application and they provided the documents. I just had to sign the application form. They said it was straightforward so it didn't take long. There were no complications to my successful application to stage 1 Skipton at that time!

213. In 2011, they added small monthly payments (totalling around £3000 a year) for those who received stage 1 lump sum payment. I was getting these stage 1 monthly payments until 2018 - until I myself discovered there was something wrong with the level of payment I was receiving.

214. When I investigated why I was not on the higher stage 2 payments (as I had suffered a B cell lymphoma cancer) I discovered that Mark, my social worker, and the hospital, had previously applied for the stage 2 lump sum payment and the higher monthly payments for me on my behalf, because of me suffering the B cell lymphoma cancer. This would have to been in 2011.

215. However, at that time, Skipton rejected the application! And I was left with only stage 1 payments! This was despite me since learning I qualified for stage 2 payments under all of the rules of the Skipton fund, having suffered a B cell lymphoma cancer, after having been infected with hepatitis C via NHS contaminated blood products.

216. In 2011, Skipton added illnesses to their stage 2 payment eligibility list, and this included B cell lymphoma. However, in the same year, Skipton rejected my application as I naturally cleared Hepatitis C.

217. I've since learned that at that time in 2011, Mark and the hospital tried many times to explain to Skipton, that their rules do say that I did qualify for stage 2 payments! It actually states in Skipton stage 2 application rules, in cases where Hepatitis C is naturally cleared but the infected victim still suffered one of the listed qualifying illnesses after clearing Hepatitis C, it is still to be assumed that you suffered the illness as a result of your Hepatitis C infection and you still qualify for stage 2 payments. However this was not accepted by Skipton, at that time.

218. This rejection position changed when the EIBSS took over, and I reapplied for Skipton stage 2 payments in 2018, after I discovered all of this, which I will talk about later in the statement.

MFET Ltd

Regular payments

219. The MFET Limited payments were put in place after the Archer Inquiry! These payments were set by the government at around £12,800 per year. But these payments increased over time as it was linked with what I believe was the consumer price index. Though I'm not certain for sure, which mechanism the payments were linked to! They replaced the much lower regular payments we used to receive, via MFT, before the Archer Inquiry!

220. The regular payments were fine as this was an automatic regular payment system. I never had a single problem with the MFET automatic method of payments! It was a much more reliable way to receive support you are entitled to than MFT grants! As there were no get out clauses for the MacFarlane trust, and no hoops to jump through to get access to support

for the beneficiary victims, this method of payment made it much easier to get on with what was left of your life - though the payment levels were still not enough to help us cope with our many illnesses!

221. These payments, through the MFET, were again replaced when EIBSS replaced all the trust funds!

<u>The MacFarlane trust reserves</u>

222. Before the MacFarlane trust was shut down, it was discovered by the government that the MFT was hoarding around £4,000,000 of government donated funding, which wasn't distributed to us, infected and affected beneficiaries.

223. The MFT claimed this money had built up in their reserves over time, and was reserves money intended for the day-to-day running costs of the trust, and it was held on to and not distributed in case the government stopped funding the MacFarlane trust! But that wasn't what the MFT were supposed to be doing.

224. Apparently the government then told the MacFarlane trust, if the MFT did not distribute this money to us beneficiaries, the money would be clawed back by the government, with the government reducing its future donations until this reserves money was used up!

225. In MFT partnership group meetings on how they would deal with this hoarded reserves of £4,000,000, the MFT told us beneficiaries that they only intended to hold one year's running costs within their reserves. But the MFT then stated that the trust's one year's running costs, at that time, should have been only around £500,000! So they clearly had hoarded the rest!

226. All the while, beneficiaries were begging for grants and being refused, and while sick beneficiaries were dying of their illnesses without this support,

which of course, we infected beneficiaries, found appalling! This became known by the MFT and us beneficiaries as the 'reserves fiasco'!

227. As the MacFarlane Trust was discovered with all this money in its reserves, it was being told by the government that it had to distribute the money, or future donations would be withheld or be drastically reduced.

228. The MacFarlane trust then made us go through a one-off grant application process. And again in the MFT partnership group meetings, which I attended, the MFT promised to us beneficiaries that they would deliver all of the £4,000,000 for this one-off grant purpose.

229. However when applying for a grant from these reserves, every participating beneficiary was forced to undergo an invasive home visit by a private assessment company assessing our living conditions. Despite our objections as beneficiary victims, this intrusive method was used to instruct the MFT on the level of our need for these grants, so that these potential grants could be costed by this private company for the MFT. This was deeply humiliating to us beneficiaries!

230. Essentially we had to figuratively drop our pants to show just how useless and pathetic we and our living standards were to this assessing company we'd never heard of, and the results of that would be reported back to the MFT. They invaded our lives and our living conditions to look for what they called 'charitable need'!

231. I found being judged in this way deeply insulting, given that it was MFT that had done wrong hoarding the money! We infected victims were put through this, all just so we could apply for a grant from the reserves money, which was money we should have already received if the MFT had been doing its job properly in the first place! We should already have received this money in support in previous years. I found it all deeply stressful and disgusting!

232. I only participated in this grant process because I was so angry at the MFT for withholding funds from our support! Many beneficiaries felt too insulted and degraded to take part, and refused to participate in the assessments! Those beneficiaries therefore received none of this support! This is because the MFT unfairly excluded any beneficiary completely if they did not agree to the assessment!

233. In my case I asked for a new roof, which was one of the few things I could come up with that was relevant to our current state of living. However, we were only allowed to apply for property-related needs. In fairness, I did eventually receive this grant for a new roof totalling around £3000. But that was not the point. What they put us through was appalling! And many beneficiaries did not benefit from any of this hoarded support money!

234. The MFT were told by the private assessment company that there were £8,000,000 worth of problems identifiable as charitable need, that they had found through the assessments regarding beneficiary living conditions, which needed to be addressed, and that initially the assessment company could immediately cost out £4,000,000 of work within the beneficiary community as "charitable need". And this was just within our living conditions, ignoring the needs surrounding our medical problems!

235. In a written complaint to the MacFarlane trust, I pointed out to the MFT that this assessment was only involving our properties and living conditions - our medical needs and personal needs would probably double those figures identified by the assessment company!

236. However, in response to the assessment companies' presented results and figures, the MFT then refused to deliver the £4,000,000 in support that they had promised for that purpose! In the end, the MFT only distributed £1,000,000 through this reserves grant process, so they put us through all that for a quarter of what they promised!

237. We were then told the other £3,000,000 would be held onto by MFT for the day-to-day running costs of the trust, even though we knew that one year's running costs had been stated to cost only around £500,000.

238. I believe once MFT did this (holding onto the £3,000,000) the government then did as it said it would! I believe the government then reduced its donations to the MFT, to force the MFT to use this £3,000,000 it was still hoarding in its reserves!

239. In essence, as a consequence, this whole exercise cost us beneficiaries this £3,000,000 in support, no less than twice! First, when MFT initially refused to distribute it and instead withheld this money from the beneficiaries in its reserves! And then a second time, when the government responded by reducing its donation to the MFT to force the MFT to use the £3,000,000 in reserves instead! Essentially as a result, losing us beneficiaries £3,000,000 in government donated funding! This whole event, wrongly punishing the already very damaged victim beneficiaries twice, for something the MacFarlane trust had caused itself!

240. This was notoriously typical of the MacFarlane trust. It was always making false promises! And this is what offended us the most. Not only did they humiliate us by coming into and scrutinising our houses, but they didn't pay out what they promised. They betrayed everyone. We went to the MFT partnership group meetings where the MFT told us about how they would distribute all £4,000,000 of the reserves funding! They even wrote to us to tell us to apply for this reserves grant process!

241. And then after all that, they categorically refused to allocate £3,000,000 of the reserves! They didn't deliver what they promised. The whole event was unbelievably traumatic to us as infected victim beneficiaries! Then the MFT acted as if they were doing us a favour!

242. The grant system is corrupt! They wanted to run the MFT like a bank or business, keeping hold of the money themselves! They tried to be a business rather than a support system. The whole thing was sick!

243. They are supposed to be a medical disaster charity set up to support infected and affected victims of the NHS infected blood products! It states this in the trusts deed! But they behaved as if they would do anything to avoid delivering support directly to us, the victims! You could become ill just because of the mental stress from trying to get support from them! It was awful trying to deal with them! And things are no better now with the EIBSS grant process!

EIBSS

EIBSS Annual payments

244. As for the current payments system, it comes straight to you. I currently get around £15,000 per year for being infected with HIV. This payment is direct and automatic. It works the same way the MFET did! There was no application involved in my case as I was already registered with the MacFarlane trust and Skipton - everything was transferred from the previous systems.

245. At the moment, as far as I'm aware, EIBSS is still paying the 'top up' payment for HIV infected victims. This payment was originally set up by the MFT. This amount varies between beneficiaries. As I believe, this is still means tested. And therefore, this still unfairly cuts out wealthier beneficiaries despite their HIV-positive infected status, treatment and associated illnesses - still relentlessly damaging their lives. I still believe this to be a desperately unfair form of discrimination!

EIBSS Grants system

246. At the moment there are around 22 categories for grants under the EIBSS. The new EIBSS grant system is no better than the grant system of the MFT. In some distinct ways, the EIBSS grant system is much worse!

247. You still have to go to them and beg for whatever grant support you need, even when you're fully medically supported by your hospital! However, now with the EIBSS, the criteria has been changed! EIBSS have made it much more difficult for disabled infected haemophiliacs to qualify for a grant!

248. The MacFarlane trust understood that the MFT grants had to support us as infected haemophiliacs, who need support because of our multiple health issues being aggravated by our infected and damaged health status, which under the MFT always included getting support surrounding disability and mobility issues, and acknowledging beneficiaries suffering from combined problems resulting from being a haemophiliac who was infected with HIV, Hepatitis C or both!

249. This complicated multiple health problem need for support was always acknowledged within the MacFarlane trust deed, prompting the MFT to have to provide grants specifically to support disabled haemophiliacs who had been infected, and deliver grants relevant to these needs! This is because being infected obviously added such radical additional pressure to our existing compromised health conditions. The MFT grants delivered this specific support in categories such as for mobility equipment, disabled adaptations, and Motability car advanced payments. That was, of course, when you could get the MFT to deliver these grants, which I've already addressed was absurdly difficult!

250. However, now under the EIBSS, the grant criteria is different and completely broken!

251. EIBSS now only allow you the grants if your hospital can specifically medically state that somehow your need for the grant is or was directly caused by your HIV, or your Hepatitis C infected status, or their treatment! But because most of our disability is of course linked to and antagonised by our haemophilia, it is impossible for any infected haemophiliac to prove that any disability need for a grant is caused by our virus infections alone!

252. This get out clause makes it completely impossible for us infected haemophiliacs to access any of the disability based grants. Despite the fact that this was the whole purpose of those disability based grants, these grants were originally designed deliberately to cater for us disabled haemophiliacs who were infected, in an attempt to stabilise our declining disability needs. As our health has always been so negatively pressured and compromised by the presence of one or more of the viruses, this is of course one of the few ways these support organisations can help us disabled haemophiliacs, since they cannot cure us of the viruses, or relieve us of the associated symptoms, or their treatments' negative side effects.

253. The EIBSS now using this new quote "Must be Hepatitis C or HIV caused need" requirement rule to prevent all infected haemophiliacs from accessing these grants, which has broken the entire grant system! This is incredibly unfair and must not continue! Our haemophilia and variety of other illnesses will always mask whatever caused any need for support, always presenting us as disabled infected haemophiliacs with multiple compromised health and disability needs, often making defining 1 individual cause (i.e. 1 of the viruses) impossible! Myself and my haemophilia unit staff have had to complain in writing to the EIBSS regarding this exact unfair new policy, which discriminates against infected haemophiliacs.

254. EIBSS must provide this grant support to all infected disabled haemophiliacs! This is of course the entire purpose of this organisation!

255. With EIBSS, the criteria to qualify is made so difficult, most of us could only manage to apply for one or two types of grants in a year. It is so difficult I'm sure most of us will simply just give up trying. But EIBSS give off the impression that's exactly what they want us to do - give up! They try anything to get someone else to pay it. And the amount of proof you have to provide is absurd. Even after putting you through this, if you

manage to get a grant, they treat you as if they are doing you a favour! They treat you badly even when they are forced into paying out.

256. I find it's never worth dealing with them to get the grants! You end up feeling so mistreated! I only put myself through this because they are supposed to be providing the support to infected disabled haemophiliacs like me!

257. Of course, I have written to both MFT and EIBSS, to complain about this grant mistreatment many times! But this changes nothing!

EIBSS mobility scooter application

258. When EIBSS replaced the MacFarlane Trust, I applied for the mobility scooter again under the mobility equipment grants. This was in June 2018.

259. On top of my application form, I provided a 6-page explanation as to why I needed it. This time it was a 6-month battle for the scooter.

260. EIBSS now say they won't give you a grant, unless it is explicitly related to HIV or Hepatitis C positive status, or treatment of HIV or Hepatitis C viruses. They refused my application claiming that my disability was due to my haemophilia! So it was not due to the viruses. That wasn't the case.

261. Also, if EIBSS can get someone else to pay for it, they will refuse to pay out. In my case, they tried to say that I needed to see an occupational health therapist. But the Council wouldn't send one, as they don't provide a grant for mobility equipment. Someone else would have given up in this situation as EIBSS made it so difficult.

262. I have protested about this get-out clause many times with both the MFT and EIBSS! I have repeatedly pointed out that infected haemophiliacs are entitled to support from MFT and the EIBSS organisations, regardless of whether any other organisation is willing to provide funding! This means

we are entitled to support from the MFT, the EIBSS, in addition to (not instead of) any other available support!

263. When applying for the grants, as dual infected haemophiliacs, you cannot prove what things are caused by. You can't prove HIV or Hepatitis C is solely responsible, as you are already crippled with haemophilia and chronic arthritis, and all these illnesses are attacking you at once.

264. But in 2018, I discovered under Skipton, the B cell lymphoma cancer I suffered 2005-2006 is listed among the illnesses Hepatitis C causes! And I had suffered significant damage to my back while undergoing chemotherapy treatment for this cancer! It was this permanent damage, which began my need to use a mobility scooter.

265. After the EIBSS's refusal of the mobility equipment scooter grant, the hospital provided two further letters (on top of the one provided with the application) emphasising that I needed the equipment.

266. In the final letter, the hospital explained that due to my cancer, with my chemotherapy treatment, I also I needed several courses of lumber puncture chemotherapy, which on one occasion needed to be attempted 7 times, which damaged my back and affected my ability to walk. Since then, this long-term damage has continued to trigger repeated and persistent painful bleeding in my lower back around my spine!

267. In their letter backing my application, the Queen Elizabeth hospital haemophilia unit insisted that the cancer was related to me being dual infected, as this was documented in my medical records!

268. I also wrote a 19-page complaint letter to EIBSS regarding how difficult they made this application, despite me having a clear medical need for the mobility equipment!

269. In the end I got the grant! And they paid for the mobility scooter. But the whole thing was appalling!

270. In the case of NHS blood product infected haemophiliacs, it was always in the past understood that the support provided would include disabled victims. The EIBSS did and continues to do everything possible to block access to the grants, just like the MacFarlane trust in the past. They are not providing the support that they should be! And they do all they can to obstruct releasing this support to us!

271. EIBSS have essentially copied the MacFarlane Trust handbook regarding the list of grants to make available. But they have not understood the reason for needing to provide all the disability and mobility grants. Neither have they understood who they are designed to support i.e. infected disabled haemophiliacs. They have to be forced into paying anything. And every time another government or new organisation like the EIBSS got involved, it's just been made harder to get access to support we should be receiving.

EIBSS Hep C Stage 2 payments

272. In 2018, I received a letter from the EIBSS, which said that if anybody had suffered any of the illnesses listed, which included a B cell non-Hodgkin's lymphoma, having previously been infected with Hepatitis C, they would already be on the Skipton stage 2 payments (now supplied through EIBSS). I thought 'Well I'm not'. I was only receiving stage 1 payment up to this time. I immediately went to hospital with the letter.

273. The current Queen Elizabeth hospital haemophilia unit staff didn't know what to do with this letter, regarding the Skipton payments I should have apparently been receiving, since Mark (my social worker) was no longer working there, as he had recently retired. And incidentally, no replacement social worker had been allocated, and still has not to this day, leaving me and other patients without a social worker's support.

274. At that point, I remember then going through the Skipton stage 2 payment qualification criteria in the earlier Skipton documents I hold. And I then discovered that it says that even if you have naturally cleared Hepatitis C, but you have suffered one of the listed illnesses, it will still be accepted that this virus contributed to you developing the listed qualifying illness. The list including B cell lymphoma cancer.

275. Fortunately, the Primary Sister who now works on my haemophilia unit, whose name is 'Pam Green', is the Nurse who administered my chemotherapy when she worked on the cancer unit next door! So she knew me well and everyone knew I wasn't lying about suffering the B cell lymphoma in 2005-2006. She was keen to get this information to them and help me apply for the Skipton stage 2 payments through EIBSS, to help me finally get the payments I should apparently have already been receiving.

276. We applied with all the medical documents and eventually, EIBSS agreed that I had qualified for stage 2 Hepatitis C payments, and therefore qualified since 2006.

277. They told me I would now get the initial stage 2 Hepatitis C one-off payment of £50,000, and that would be paid into my EIBSS bank account since as I was already aware this account has to be kept separate from other bank accounts.

278. The monthly payments were only available from 2011. But EIBSS said they would only pay me monthly stage 2 payments starting from 2018, and claimed they could not backdate my payments to 2011. Obviously I found this to be unacceptable, as this meant a difference of around £97,000 over that length of time, which they were now saying they were refusing to pay me.

279. Of course I immediately appealed that decision as they already told me that I qualified from 2006, and therefore should get monthly payments from 2011 when they were first set up!

280. By researching my papers, I had to discover for myself that the Skipton qualifying process said that if you disagree with their decision, then you should appeal and take them to the Court for the case to be reviewed by an independent judge. EIBSS told me none of this information!

281. Because EIBSS refused to back pay my Skipton stage 2 payments, I had to threaten to take them to Court to get what I'd always been entitled to. After they already acknowledged they should have been paying me from 2011, they were trying to take a total of £97,000 away from me! I handled most of this over the phone.

282. Once I'd threatened to take them to Court, I got another letter stating that they accepted I should have been paid since 2011, and they would now pay a total of £147,000 into my bank account, which would include the £50,000 one-off payment and £97,000 in backdated monthly payments. If I didn't make a fuss they would not have paid, and I would have lost £97,000!

283. I genuinely believe EIBSS tried to use their policies to swindle me out of this Skipton stage 2 support money, which they themselves said I had qualified to receive!

284. As I stated previously in this statement, having spoken to Mark, my former social worker, my haemophilia unit later informed me that my social worker had previously applied on my behalf to the then Skipton fund to try to get me these stage 2 payments.

285. As I said previously, when my social worker and hospital staff attempted this stage 2 Skipton application, despite the evidence and the rules of applying being the same at that time, this earlier stage 2 application was rejected, which I now understand was wrongly rejected! This was why until

recently I was left on only stage 1 payments, despite my social worker's best efforts! The whole ordeal was another very stressful and disturbing experience!

286. Of course, if I had received them at the time, the payments may have gone a long way to supporting me through my recovery from the cancer! I was denied this until now!

287. This makes me feel even more mistreated, frustrated and appalled by these so-called support schemes! They care more about their get-out-clauses than the victims they're supposed to be supporting! And nothing has changed now EIBSS has taken over!

EIBSS payment concerns

288. I have two concerns which are related to the EIBSS payments.

289. Regarding the MFT, Skipton payments, tax and benefit waiver, firstly, there is a job centre plus document, which outlines this benefit waiver and its rules! The document states that any payments from these organisations, and any associated income from investments relating to these payments, is exempt from inclusion when calculating tax and means tested benefits.

290. Since being with the MFT and Skipton, I do hold a version of this document from 2006, and an updated one from 2010, including new benefits that were added.

291. This 2006 and 2010 benefit waiver outlined when receiving payments, who would benefit from the waiver and who would not! All Primary infected beneficiaries, our partners and our children were covered by this waiver. I need to know if this is still the case with EIBSS.

292. We, EIBSS beneficiaries, were informed by the government that this benefit waiver would still apply to payments from EIBSS. We were not

instructed there would be any changes at all to this waiver! But EIBSS refuses to provide to me a document supporting this to still be the case with EIBSS payments!

293. I believe it is necessary for us to have a new version of this document that includes the new organisation and any new affected benefits, outlining our legal rights and responsibilities regarding this benefit and tax waiver, as was previously provided to us by MFT. However, despite my requesting it many times since EIBSS took over our payments, this document has not been updated by EIBSS or any government organisation to include EIBSS and its payments, nor has it been updated to include any new benefits such as universal credit.

294. I have been trying to get the EIBSS to update this benefit waiver to include the new organisation, since EIBSS took over from the MFT and Skipton! However EIBSS is refusing to do this. They have told me repeatedly the government will no longer update this waiver document but do claim we beneficiaries are still covered by it!

295. Because EIBSS, refuses to redraft the tax and benefit waiver, I no longer know who is covered by the benefit waiver, regarding the new organisation EIBSS, and who is not! I therefore have no written proof that the benefit waiver still covers me and my next of kin when we receive EIBSS payments!

296. Secondly, in 2018 the EIBSS website used to state that there is no need to declare these payments to our benefits office or tax office. But EIBSS has changed this now, now stating on the website that beneficiaries should declare all payments received to one authority but not to the other. Even more confusingly, EIBSS also sent a few letters recommending that we should declare our payments to both authorities.

297. I have requested a document from EIBSS to make things clearer, so that I am not accused of fraud because of declaring my payments in the wrong

way. But EIBSS is refusing to give me an updated tax and benefit waiver document.

298. They now claim they do not have a copy of this document to give me. But their website states that they do have and will give me this document!

299. Since my enquiry, EIBSS have now as of January 2019 altered its website to say that we do now need to declare our payments to the benefits office when claiming benefits, but do not need to declare payments in the case of tax and the tax office. They changed this as a direct result of my enquiry!

300. However, also, I recently discovered in early 2019 that official benefit claim forms, such as carers allowance still state on their front cover "Do not declare payments from the MacFarlane trust". I am deeply concerned and confused! Without an updated benefit waiver document, I do not know whether I should declare EIBSS and not declare past MFT and Skipton payments, or if I should declare both organisations payments past and present, or neither, because EIBSS refuses to resolve this issue by producing an updated benefit waiver. I do not know how to protect myself, or my family regarding this EIBSS payments, tax and benefit issue. And that worries me. We do not wish to commit any form of fraud by declaring things wrongly because we were not informed correctly by the new EIBSS organisation! I just want to know who is protected now under the tax and benefit waiver!

Section 8. Other Issues

301. The Scottish payments system is delivering more money to individual victims in the same situation, and our government has not acknowledged us in the same way. This is very unfair and discriminates against victims living in England, simply because of where we live. The NHS is UK-wide, so everybody got the same infected treatment and were infected with the same viruses. Why are we, victims in England, being treated differently and basically being financially shorted? The government always seems intent on attacking us, and always seems obsessed with reducing

amounts of support in any way it can, or trying to reduce the numbers that it provides support to by excluding entire groups, such as bereaved parents of infected children, who have since died. This is while the government claims it is delivering fair support to all victims. The government delivering lower amounts of support to victims living in England, compared with Scottish victims, is appallingly unfair, and it is just another example of the government's desperately unfair discrimination against infected victim groups. This needs to be addressed by this Inquiry. There's no reason to treat us so unfairly just because we live in England and not in Scotland.

302. The old trusts and new organisation, EIBSS, make it impossible to get anything from the grant systems! Even when we're fully backed by our hospitals, we're not even allowed to use the term 'compensation' because it would mean admitting liability for the government! So it's just called charity money. But we are not charity cases! We are victims of negligent NHS treatment practices! And we continue to be treated appallingly by these various, old and new, payment organisations!

303. It's not just physical damage, it's obviously 30 years of emotional and mental damage, as much caused by the endless stress and anxiety of dealing with the support schemes as caused by the viruses and the damage they cause themselves. Even with what has happened with me, through the American litigation case, in addition to the UK HIV Haemophilia litigation case, I don't feel adequately compensated for all of this lifelong damage.

304. However, as of 2018, I am now getting something that I can somewhat function with as I now get both HIV and Hepatitis C high rate payments, despite this being made incredibly difficult for me to get. Most infected victims do not get this higher level of financial assistance, which leaves them still in desperate need of much more substantial financial support!

305. As to this financial assistance, if someone is infected with one virus, they don't get enough to try and stabilise their life. With just one virus, there's no way any of us are stable on just the £15,000 payments. Or even if you're infected with HIV and Hepatitis C, but get only HIV and stage 1 Hepatitis C payments, it's difficult to support yourself with this low level of financial assistance, especially when so many unpredictable illnesses can hit you randomly at any time. With all that pressure, as well as normal daily living problems, it's hard enough to get by, surviving day-to-day, without all the additional financial pressures.

306. Most victims will be forced to rely on the grants, which are deliberately made almost impossible to get. And this makes me furious as I spent many years trying to deal with this unreasonably, corrupted and unfair grant system! I want the grant system to be gone and the payments to be much higher for all victims, providing to the victims equally and fairly! I also want the payments to be automatic so that they cause no additional stress and anxiety to the victims.

307. Further, my cousin died when he was 12 years old, which means my aunt has never received any payments since 1992 despite the fact that her son was killed. That fact has angered me ever since I learned about it! The MacFarlane Trust always had a policy that excluded and abandoned those parents whose infected children have since died. I want that addressed majorly as it is completely unreasonable to exclude parents of children who are killed from any settlement, charity or support organisation's system. It enrages me that nothing has been received by my aunt, in my cousin C name since his death! He should be entitled to support in his name to provide for his family as they lost him and still have to live with that grief!

308. Also, I don't want the government claiming that they learnt their lesson and stopped using the products that were dirty. They continued using the dirty products even after HIV testing was introduced. They proved this when the NHS, run by the Department of Health, infected me at the end of 1986 - proof that dirty products were still being used! The NHS claimed

they were heat-treated Factor VIII blood products - I don't know whether they didn't do this heat treating to destroy the viruses. But the NHS didn't test the product batches, even after so many had already been infected in previous years. None of the batches were being tested to see if they were clean. Otherwise, the dirty batches would have been identified and destroyed!

309. Even though the NHS had infected people on multiple occasions, across two decades, it's not like the government changed its approach after it was discovered that NHS blood products infected so many people - they just carried on purchasing cheaper, dirty American products and continued infecting people! That is unforgivable!

310. The government even scrapped plans to build our own treatment manufacturing facilities in this country that would've provided clean blood products - they could have tested and ensured they were safe! I believe this was planned to be built in an area called Ladywood! But the government scrapped this plan because they said it was too expensive, and it was cheaper to continue buying the dirty American products! Apparently we just weren't worth it!

311. Obviously, whatever comes of this Inquiry, if the Inquiry establishes that anybody within the NHS, Department of Health and government, at that time knew they were infecting people and still deliberately continued to expose victims to contaminated products, regardless of the consequences to us the victims, effectively guaranteeing infection, then it has to be recognised by the Inquiry that those actions were evil. And justice for those actions has to be delivered! But just as importantly, as the infected victims, we need all guilty parties who turned a blind eye and continued to let infection happen to victims through the purchase and use of contaminated blood products to be identified by the Inquiry! Then those people responsible for this horrific, deliberate negligence need to be held accountable. And the victims need justice for that too.

312. It would be right for the Inquiry to get clear and full numbers of how many have been infected by this infected blood product disaster, and also accurate numbers of how many victims have died so far.

313. There are lots of people who can't tell you how bad this was for them. We can't protest against this horrendous, negligent mistreatment in a normal way in large numbers, because most of us victims are dead.

314. If only six people turn up to a protest, that's only because many hundreds into the thousands have already died! How do you protest in the mass numbers people would take notice of when there's only 200 of you left? Not to be crass, but we can't drag the dead victims' gravestones to the protest! So we need this Inquiry to protest against the horrific way we've been treated (for decades now) for us. I don't think you can say it clearer than that! It's not just about me! It's about everybody that's died! And their bereaved families too!

315. No other form of NHS treatment is done with dirty products. If an NHS surgeon had infected just five people, by re-using dirty, infected surgical equipment, that surgeon would never have left a prison cell!

316. Why were we treated like lower life forms? We apparently didn't deserve clean treatment. That's just not right! It causes us victims a lot of stress and frustration on top of our continually declining poor health, and nothing's ever been done to address this great crime against us infected and affected victims.

317. What bothers me as well is the government is in the process of trying to do very similar things again, to what caused what happened to us! They are ripping the NHS apart again, because they're obsessed with financially penny-pinching. It makes me worry they are going to cause some other cost-related NHS disaster!

318. If we can make them have to deliver justice over this, they may be forced to learn lessons and not do the same thing again next time. Or it will at

least take them a long time before they fall into such shameful behaviour again.

319. I do also want to know why we were considered not worth clean treatment for so long, so many times. They should have been testing the products, and should have been destroying any products that were contaminated!

320. I know around three-quarters of the HIV infected haemophiliacs, from the MacFarlane Trust's catalogue, are now dead - a great many as a direct result of their being infected! I know we're down to about 200 out of about 1500 people who were originally infected. And that's just the HIV infected victims registered with the MFT! There are huge amounts more victims that were infected with the Hepatitis C and B viruses, many who have also died!

321. The government can't pretend we stopped dying! We have continued to die off! Each of us, HIV-infected, are registered with a number with the MacFarlane Trust. The MacFarlane Trust's own catalogue of our currently surviving numbers proves how fast we've continued to die off at an abnormally high rate! The records say we're dropping like flies! And there's barely any of us left.

322. Even when we're relatively well, we're around the corner from something bad! That's the way it works. We can never know when that final deadly illness, sparked by our infections, will happen to us! It seems like we are always trying to survive, on a knife edge!

323. Essentially, when it comes to this Inquiry they should get on with it, as quickly as they can, because of how long it takes. It's known some infected victims won't make it long enough to see this Inquiry bringing justice to us!

324. But it's hugely important to all the victims that you find out who was responsible for what happened to us, and get this Inquiry right. We need you to deliver whatever justice is warranted by your findings!

325. Many people won't be able to interact with the Inquiry in the way they want. Not only are we very emotionally raw, there's 30 to 40 years of ongoing trauma to tell you about - the effects of this trauma arising in such a wide variety of ways. We wouldn't know where to start or exactly what the Inquiry needed to hear, so I'm immensely grateful for all your help in helping me draft my statement. I just wanted that on record!

326. But please do not think any victims not responding to this Inquiry aren't doing so because those people were not damaged, when someone in their family was infected! Far from it! It will in fact be the case that if they don't respond, it's because dragging up the past will cause them far too much emotional pain and they just can't face it again! But even those victims who do not respond to this Inquiry are still just as entitled to see justice done, for what they have had to endure thanks to the NHS contaminated blood products, infecting them and destroying their lives. Please remember, the Inquiry's acting for all of these victims, which also includes the ones who have passed away!

Statement of Truth

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

Signed **GRO-B**

Dated 25/03/2019