Witness Name: GRO-B
Statement No.: WITN0385001
Exhibits: nil
Dated: 28th February 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 9th 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 GRO-B

2. My address if known to the Inquiry. I am a secondary school teacher, currently working in teacher training, and live with my partner of 22 years. Until leaving university I lived with my parents in GRO-B GRO-B and this is where my parents continue to reside.

3. I intend to speak about my mother and late brother.

4. In particular, I intend to discuss the nature of their illnesses, how the illness affected them, the treatment received and the impact it had on them and our lives together.

Section 2. How Affected

5. I am a carrier of Haemophilia but have been infected with neither Hepatitis nor HIV.

6. My brother contracted both Hepatitis C (aged 4 - Hepatitis /Australian Antigen Positive), and HIV (diagnosed with HTLV3, aged 12). We

presume these were the result of treatment (Cryoprecipitate or Factor VIII) provided since birth for his severe Haemophilia A (less than 1%).

7. My mother was diagnosed with Von Willebrand's Disease in her later teens. Despite her and my father being told by the same haematologist that any future off-spring would experience nothing worse than her symptoms, she found out that she was a carrier of Haemophilia A on the birth of her first child (my brother).

8. My mother was infected with and continues to have Hepatitis C. She was diagnosed with Non-A/Non-B Hepatitis while in hospital, having become unwell following a family holiday to Florida.

9. We presume she became infected in the course of receiving treatments to boost her low blood clotting level prior to/during/after operations such as a full hysterectomy or gall bladder removal.

10. My brother received blood products including: Cryoprecipitate, Hemofil, NHS Concentrate, Profilate, Koate, Factorate, Heat Treated Profilate, Alpha Concentrate, 8Y, Gamma Globulin, AZT, Monoclate-P and 8SM. (Home treatment records transcript available, including the majority of product names, relevant batch codes and quantities).

11. Treatment and care was provided for both my brother and mother at the main local city hospital's Haemophilia Centre

12. Treatment was also provided by the Dental Hospital as well as other hospital wards, for instance before home therapy began and when my mother was unavailable.

13. Treatment was also given to my brother on one-off occasions at hospitals in London and Edinburgh.

14. Treatment was also provided whilst he was on a Destination Disney trip to Florida, USA. A year later, on a family holiday to Florida, 20 bottles of Alpha Concentrate List Number: 420410 were delivered to our hotel (possibly by the Pharmaceutical Company) for use during our vacation. (6 were used while in America with the remainder being brought back and used once in England).

15. A doctor from the main city hospital is currently monitoring my mother's Hepatitis C. She has received treatment from the Haemophilia Centre and other wards there. She has also had stays in the two other local hospitals so may also have been given blood products there.

16. My brother was treated for a bleed into his head at birth and received blood products consistently throughout his life.

17. My mother received treatment during various hospital visits including: the forceps birth of my brother, and uncontrollable bleeding following

the birth of myself, a full hysterectomy, gall stones removal and surgical bladder repair.

18. The risk of infection was not made clear to my parents (regarding my brother or mother's blood product usage) prior to infection. When my brother was first born, my parents were told that he had arrived at the right time, as we were becoming self-sufficient in terms of blood products.

19. Hepatitis was not raised until my brother became ill aged about 4 years (diagnosed with Non-A/Non-B Hepatitis, and Australian Antigen Positive).

20. My mother's personal notes from the time indicate blood tests and liver function tests for my father, brother and myself, with the possibility of anti-Hepatitis C Globulin for my father, mother and myself. Such treatment was never mentioned again so not given. If it had been, my mother may not later have been infected with Hepatitis.

21. Eight years later my mother has noted that a three-stage family injection was available that would cover us for five years against Hepatitis, but again we were not offered nor given this treatment.

22. My mother has no recollection of being told anything about the possibility of, nor how to limit, infection. When my brother was first poorly it is likely that a number of tests were carried out but, as parents who respected the professionalism of the medical staff, questions were not asked at the time. The only overt advice that was provided was before my brother was diagnosed with Hepatitis. This was to ensure precautions were taken at school and the like, if he experienced any blood loss. For example if he had a nosebleed, then everything was to be bagged-up for my mother to dispose of. Despite this, at no point was my mother advised to wear gloves when treating my brother.

23. Haemophilia Centre staff, informed my parents of my brother's HTLV3 diagnosis, when he was aged 12 approximately. Again, little can be recalled in terms of specific advice apart from being told that no one else was to drink from the same cup as him and that he was to have his own cutlery. Such advice instilled fear into my parents who felt they were being told to be afraid of and ostracise their own son. Still, however, my mother was not told to wear gloves when giving my brother his home treatments.

24. My mother was diagnosed with Non-A/Non-B Hepatitis while in the local city hospital when she was aged 40. The medical staff initially suggested she had picked something up from Florida, until she was eventually given the same diagnosis as my brother. This was possibly by a doctor from the Haemophilia Centre. It was from this point that my parents felt *dumped* by the Haemophilia Centre, for instance being

told that it would clear up in a few weeks. My mother was not even informed that having unprotected sex with her husband could lead to my father becoming infected.

25. My mother has noted on 10th May 1990, that there was an item on the radio saying some Factor VIII was being withdrawn because of a risk of Hepatitis B. The following day she telephoned the Haemophilia Centre to check our supplies were not affected and was told that they were okay.

26. Information, advice and guidance regarding infection, managing it and the possibility of further transmission of infection was therefore scant.

Section 3. Other Infections

27. Except for those mentioned, my mother and brother did not receive any other infections as a result of receiving infected blood products.

Section 4. Consent

28. As my brother was a minor he was not consulted before tests for Hepatitis or HIV, but due to relevant symptoms the Haemophilia Centre did carry out such tests.

29. I have no reason to suspect that tests were conducted for purely research purposes but my parents do not recall any overt disclosure of the focus of tests, especially not for Hepatitis.

30. This may have been different regarding HIV as my brother rejected a drugs trial (for AZT) when it was being conducted. He saw no clear benefit to himself as he either could be getting the drug or may not be.

31. My mother was in hospital for two weeks in a lot of pain, feeling sick, unable to eat and hooked up to two drips for a period. She was not aware of being tested specifically for Hepatitis, as staff focused on it being something she had picked up from Florida. It was only later that she was told it was Hepatitis.

Section 5. Impact

32. My brother was a very resilient individual who was somehow able to accept the medical challenges he had been dealt.

33. Despite being a severe Haemophiliac he refused to let his condition limit his experiences, so was physically active throughout much of his youth. He secured many swimming badges, including his mile and Life Saver Award. His attendance at a local gymnastics club resulted in him being awarded the for Sporting Achievement. My brother was also an active Cub and Scout, going on walks and camps including the Cheviot Challenge, and Brass Monkey

in Scotland. With the support of the school's Geography Department he experienced the likes of caving and abseiling as well as completing the Bronze Duke of Edinburgh Award.

34. My brother was a well liked, easy-going and sociable young man, often having school friends around to the house, as well as spending time with fellow radio controlled car enthusiasts. (Another successful endeavour as he won some local competitions).

35. He continued to socialise with his friends, going out to pubs, clubs and music events, until his declining health and energy levels prevented this.

36. Despite appearing a happy and active young man, my brother's medical status meant that he never had a girlfriend.

37. A slightly enlarged liver, noted by a Haemophilia Centre doctor when my brother was approximately 11 years old, indicated his Hepatitis C.

38. My brother was diagnosed with Shingles in his face and admitted to hospital in his mid teens.

39. My brother starting AZT treatment and being admitted to hospital with T.B. (M.A.I.), in his late teens, showed more significant negative medical changes.

40. Having an ankle bleed for three months indicates the reduced impact of my brother's treatment. On-going shin pain also indicated of his body starting to fail.

41. A bone and full body scan were completed four months before my brother died but he rejected the bone biopsy, which had also been suggested by the Haemophilia Centre doctor.

42. Throughout his life and as his preference, my mother administered my brother's home treatments and attended all hospital meetings, check-ups and the like with him. Yet he was confident to make his own decisions about treatment.

43. My brother's home treatments, as well as his overall strength and mobility, declined within the final years of his life. Despite improved assignment grades, the effort required to attend university became too great, so he was forced to leave university four months before his death.

44. My mother administered his final home treatment three months before he died.

45. As his strength waned and the pain increased, my brother spent increasing amounts of time wrapped in a blanket in the living room or

in bed. The pain medication he was being prescribed for his leg increasingly *knocked him out*. He was also taking vitamin K at this point.

46. Even during this period my brother could still be relied on for a smile, sharing his true fears and pain only with my mother, his confidante throughout his whole life.

47. He eventually became bed-ridden, with the whole family often spending time with him chatting and trying to distract him from his discomfort.

48. As his pain relief was increased still further his lucidity and periods of consciousness declined.

49. My brother died at home, with my mother by his side, aged 20.

50. It was felt at the time that the Haemophilia Centre provided all possible treatment options for my brother. Some, such as a Sister, did their utmost to help wherever possible, including her coming to the house to visit my brother in the final stages of his life. It is very likely that it was also she who had organised access to treatment via a pharmaceutical company (delivered in a plain brown paper package to our hotel) during our family holiday to Florida.

51. My mother has felt the extreme weight of her Hepatitis C status since her diagnosis aged 40.

52. The stigma has never diminished and events, such as the current inquiry or visiting the dentist, bring her diagnosis to the fore all the more powerfully. This is part of the reason why she has been reluctant to engage with check-ups and related scans. She would often prefer to remain in ignorance of the possible impact of Hepatitis C and be left alone to *get on with life*. Yet this decision causes her guilt and psychological trauma for fear of letting her family down. Thankfully, she appears not to have suffered any overt symptoms related to Hepatitis C as yet.

53. Following my brother's death and a change in leadership at the Haemophilia Centre, she and my father felt rejected by the Haemophilia Centre, so she largely disengaged.

54. It was only once my father started seeing a relationship psychologist that my mother was linked to a doctor initially working at a different local hospital. It was this doctor who gave the support the Haemophilia Centre had not provided, and is someone my mother feels is understanding and willing to listen to her concerns and fears.

55. The most significant impact of my brother's Hepatitis C and HIV status was the shortness of his life, dying at the age of twenty, following a prolonged decline and a great deal of pain.

56. The emotional struggles he had to endure I cannot account for, being a very private person and someone who could present a *normal* exterior. As his younger sister he protected me, not sharing his thoughts and feelings with me, despite our sharing a great deal of love and respect for one another.

57. Although I was often my brother's shadow in our younger days, enjoying being a tomboy playing with him and his friends more than my own, we became increasingly distant in our teenage years. This was possibly an element of him preparing me for what was to come.

58. He shared his thoughts with my mother who was the one who administered all of his treatments and attended every hospital visit with him. It was she who had to provide the awful answer to his question of, 'Am I going to get better?' after one such visit and, as things got worse, listen to his description of his increasing pain levels and not be able to adequately help him.

59. If my brother did feel anger or frustration with his health situation he did not express it openly at home. This may have contributed to the sometimes-challenging interactions he and my father had. They could come at things from different angles and the underlying 'elephant in the room' would not have helped. It may simply have been that he was an adolescent and tensions between children and their parents naturally surface at this time of life. Without time on our side, we will never know.

60. My brother had a strong group of friends around him, but whether he spoke to them of his status and associated emotions I do not know. There was one friend in his later years that had health issues of his own. My brother commented to my mother on one occasion that sharing a similar life experience of being different was helpful for him.

61. As stated above, my brother's medical status prevented him from pursuing relations with the opposite sex so he never had a girlfriend and most probably never even experienced his first kiss.

62. My mother has struggled with her Hepatitis C diagnosis, feeling tainted and dirty. Seemingly simple things, such as visiting the dentist, reinforce her inequality as she has often been given the final appointment of the day. This is so the risk of infection to others is diminished.

63. Her Christian faith has been of great solace to her but even the taking of Communion acts as a reminder and stumbling block. Unless she

sits at the back of the church, and is therefore last in the queue for the bread and wine, she fears she will put others at risk of contamination.

64. At present, when she is fighting hard to keep her clinical depression at bay and in the current inquiry context, she has stopped attending certain services. This is to avoid the need to make excuses for not sitting with her friends towards the front of the church, thus further undermining the emotional and social support systems so vitally needed at this difficult time.

65. As well as the personal shame and emotional trauma, Hepatitis C has not helped my parents in their marital relationship. As someone who, for reasons both physical and psychological, can struggle with romantic intimacy, the added stigma of Hepatitis immediately undermined my parents' sexual relationship. They love each other so very much but for many years have struggled with sexual contact, becoming more like friends than lovers. Especially as my mother's physical health problems increase and my father adopts an ever-greater caring role.

66. My mother is too ashamed to share her Hepatitis C status with friends or wider family, so is only able to talk about her emotional difficulties with it and fears for her physical future (exacerbated by some of the recent media case studies) with my father and myself. Clearly this changes family relationships, adding emotional pressure and responsibility, as well as limiting her chance to access wider support networks.

67. Having my only brother living with and eventually dying from HIV and Hepatitis C, then later learning that my mother also has Hepatitis C has undoubtedly affected my life in many ways.

68. As a girl, I always knew my brother and, to an extent, my mother and I were different because of our connection to Haemophilia. Regular trips to the hospital, playing at the Haemophilia Centre with the boys on check-up days or at the Haemophilia Society Christmas parties, meant hospital was a common theme throughout my childhood.

69. I was used to treatment bottles in the fridge at home, watching my mother inject my brother and him being in splints or bandages and in pain when he had bleeds.

70. Such normality did not seem to change even once my mother told me one lunch time, that my brother was HIV positive. I was at secondary school at the time and knew what it meant. I was upset but still went off to school for the afternoon as usual and life continued. Knowing what can and, as my parents were told, most probably would happen is very far removed from experiencing the reality when the time comes.

71. My parents did a wonderful job of keeping me informed of key details, while allowing my brother and I the space and freedom to live our young lives. I always knew I could ask if I wanted to know more but never felt the need as they got the balance right. I felt then that knowing what was to happen would help me manage the situation and that I would be able to cope. I believed myself to be mature enough to handle what was to come and, on the whole, was able to keep myself in check throughout, being well behaved, working hard at school and continuing to dance 4-5 times a week.

72. I continued studying, dancing and working in a hotel while my brother was dying, however not one of my friends knew what I was living through. I had never told them he was a Haemophiliac let alone that he had HIV.

73. The late 1980s and early 1990s was not a time to share such sensitive information and I had been raised in a family where some things remain private. I can recall one of my brother's peers asking me when I was younger if he had 'green blood'. Even at an early age this was sufficient for me to understand what should and should not be shared.

74. In addition, my mother had a number of hospital stays throughout my youth and, although many were for relatively routine medical problems, some were to different kinds of hospital (later I understood these to be mental health wards or facilities) so again, not spoken of publically.

75. Such secrecy can have many consequences. Not surprisingly my school friends were stunned when I had to tell them that my brother had died, as they did not even know he had been ill. They and most others will still believe that he died from pneumonia, the selective story presented at the time, written on his death certificate and continuing to go largely unchallenged locally by myself and my parents.

76. I began my first relationship, again when my brother was in his final months. This boyfriend was the first and only peer I told about the reality of my brother's medical status and my home situation. He was sworn to secrecy, but was a vital source of escape during a very difficult time in my life. The end of this relationship a year later meant that the only person who experienced that time with me is no longer part of my life, others, including my partner of the past twenty-two years can only imagine.

77. I have had periods where events have caught up with me, which led me to seek counselling during my time at university, and having what could be termed a breakdown early in my career. I have got through each difficult period with the support of my parents, partner and

friends and have increasingly learnt to see such challenges as opportunities for growth.

78. In my opinion, my father has also struggled, having to grieve and let go of his anger in the short term but continuing, even now, to question whether he and my mother 'got it right' for my brother and I. Now he takes medication for anxiety but manages well overall (although this inquiry is taking a heavy toll).

79. It has taken time and geographical distance, whether while at university or in my life now in Wales, to allow me to open up and tell people who never knew my brother the truth. The number of those I have been honest with only just reaches double digits. Even now information is only shared once trust has been established, and with the caveat of it going no further.

80. My family situation meant I became emotionally independent, learning not to discuss things or rely on people beyond the nuclear family. I developed a belief that life is a continuous struggle. I can lack confidence and self-esteem, especially in social situations, and am not always fully open with my feelings, even with my long-term partner whom I love very much.

81. I can be guarded and struggle to let go. My partner knows all about my family history and loves my parents and I just the same, which is wonderful. Although I want to spend the rest of my life with him, I know that I cannot to commit to marriage as it feels like giving up my independence and, somewhere inside me I want the family name to die with me.

82. I also do not want to have children. There is a range of reasons for this, but one is my fear of not being good enough. Having seen the challenges my parents have lived through, and how well they did in bringing my brother and I up I do not feel capable of similar feats. Increasingly I recognise that I often avoid some of the more traditional and/or key responsibilities of adulthood.

83. The short-term ramifications of my brother's death were huge for us as a family, as not only had he died but also my mother had lost her own mother two months prior to this. I was about to leave home for my first year of university. Empty nest syndrome had an even starker reality for my parents.

84. My father did not want to leave me at university and, my mother, who had been declining since my brother's death, soon spiralled into a severe depression. She was physically and emotionally exhausted, having cared for her mother and my brother so diligently and, in her view, she had failed in her role as a mother to protect and save her son. She lost the will to go on and was sectioned that autumn,

something that would happen on a number of occasions over the next few years.

85. It was yet another loss for us, my father losing his wife and I my mother to depression. Although strengthening the bond between my father and I, our family life has been dominated by depression ever since. All too often my father has to adopt the role of my mother's carer and I have increasingly taken on the same role, becoming a confidante and source of support. We have an amazingly open, honest and supportive family relationship for which I am very proud and grateful, but such honesty is not without its pains. How many husbands or children want to know their loved one has suicidal thoughts let alone have to help them navigate such horrendous periods?

86. My mother has worked hard to come off anti-depressants and loves life, but we all remain on a tightrope. When will the negativity take hold again and how far down will she go? She has seemingly never ending strength and resolve, managing to drag herself from the depths of despair so often. She is compassionate and caring, always putting others' needs before her own, and is well loved by those she meets. Such positives are forgotten in an instant however, as seemingly small things have massive repercussions.

87. This inquiry has taken over her life as she re-lives the death of her son and her associated guilt over and over again. As his mother she believed, and still strongly believes, herself to be responsible for his status and death. She is the Haemophilia carrier who gave birth to him and she was the one to administer his treatments. Having thought she was giving injections that would improve his quality of life, which is correct, she now cannot shake the notion that she was actually killing him. The guilt my mother carries is crushing and refuses to go away. She can have periods of acceptance but her depression prevents her from truly moving on so, as a family, we continue to tread old ground at regular intervals.

88. From the announcement that an inquiry would be held it has dominated our family life. This was not something any of us wanted. My mother had worked hard to move forward so was happy with David Cameron's apology. Although answers would be nice none of us expect much from the process and financial compensation is irrelevant.

89. We cannot ignore what is taking place however and feel it our duty to do what we can, but each letter through the door or item on the news can destroy my mother's mood. She and my father are exhausted. The anxiety of what may come and how long it will take is too great. My mother wants passionately to speak out and share her story, but has had to take the difficult decision not to as her marriage and mental health are too precious to risk. She and I have spent hours

transcribing my brother's treatment records so she can at least provide some evidence to the inquiry. Going through his life in this way has not been easy and, again, re-living that time has been emotionally challenging for us all.

90. The stigma associated with my brother's HIV diagnosis in many ways feels undiminished for us as a family and especially, in my opinion, for my father. In his traditional male role it was his duty to protect us but how could he shield his family from the onslaught of media messages at the time?

91. In the 1980s when HIV/AIDS first came to light, it was new and frightening as so little was understood about it. Here was an infection portrayed in the media as a gay plague and associated in the minds of most with homosexual sex and drug use, hardly an easy environment for any family to deal with.

92. The government health campaigns, although fulfilling a vital role, made matters even worse as the adverts, posters and leaflets were everywhere. How could a father protect his children from such an onslaught, which reinforced in such dramatic terms the ultimate price suffered by anyone who was HIV Positive?

93. The last thing my father wanted was to have his family, and his son in particular, constantly reminded that he was going to die. Yes, the population needed to be warned and encouraged to act sensibly, but such scare mongering left no safe space for the victims of HIV. All were tarred with the same brush and peoples bigotry and fear led to some horrific public displays.

94. I was lucky; my parents did well to shield me from a lot of what was going on. Our family secrecy helped to protect us, unlike those who suffered the graffiti, assaults, loss of employment, social isolation and the like.

95. Even today all three of us remain cautious about what we say, and who we say it to. If my brother had died from cancer things may have been very different but, despite the best efforts of campaigners and charities, HIV/AIDS continues to be viewed by many in old-fashioned stereotypical ways. It is something that affects *other* people, distant and irrelevant to the majority. HIV/AIDS is either ignored or referred to in jokes, as having AIDS is still a common theme for teenage insults and humour, despite their not having been alive when HIV/AIDS first emerged.

96. I feel that for my father, the inquiry has brought the fear and anger associated with the government's lack of consideration for victims at the time to the fore. He was a coiled spring, always on guard, looking out for how to shield his young family from attack or social isolation, while trying to learn about what was going to kill his son. He can admit

now that he was terrified but managed to hide it from us at the time. Constant vigilance and the fear of being found out was his focus for years. His role in this family crisis was different from my mother's and this naturally affected their relationship. They often fulfilled their parental duties in relation to my brother's HIV status separately – a united front but emotionally distant from one another.

97. The fear of how people will react if they knew our HIV past is still a worry for my father, hence the anonymity here. At the time he shared the truth with only two people. He relied for the most part on speaking to professionals (social workers and the like) when the burden became too great. I have been heartened that the inquiry has nudged him to let two or three more people closer to the truth but again, they have been carefully selected and it is possibly too late for him to believe that attitudes towards HIV/AIDS have really changed. The stigma level remains undiminished in his mind.

98. In addition to HIV, Hepatitis C carries stigma also. My mother noted when my brother was still very young that the Haemophilia Centre doctor received a letter from the Department of Education, stating that he must be permanently removed from nursery school, due to his Hepatitis. This was in case an epidemic broke out for which they would be held responsible. I cannot imagine the anger and humiliation she and my father must have felt, when faced with such official conduct and having to disclose his medical status to future schools. Here was a boy who was different, not only because of his Haemophilia but also because of his Hepatitis. He was a student for whom special precautions must be taken, such as bagging blood stained handkerchiefs, if he fell or had a nosebleed.

99. As a child I was largely unaware of Hepatitis, my brother's Haemophilia and eventual HIV being the main concerns.

100. As an adult my mother's status was discussed more openly, as she had to make decisions about tests and the like.

101. Her Hepatitis C is something I have shared only with my partner, as she is ashamed of her status. It is an infection little understood or discussed in society but my mother describes how it makes her feel dirty and tainted and, as someone still living with the infection, she has the right to privacy so it remains another family secret.

102. As previously mentioned the reality of my brother's illness was a closely guarded family secret, so for my grandparents, for instance, his illness and eventual death was unfathomable (they were not told he had Hepatitis nor HIV).

103. My Granddad, having lost his wife and Grandson in the space of three months was heart-broken. For a fit healthy octogenarian, the loss of someone so young was something he believed to be out of the

natural order of things. He then had to cope with his daughter being kept in a psychiatric ward on more than one occasion, again compounding his confusion and impotence.

104. My brother was a capable student and secured both good GCSE and A Level results, despite his health issues, and began a BSC in Computing. He had a very understanding university tutor, in my mother's opinion, but my parents were warned by doctors that my brother might not live to see Christmas of his first year. He defied the odds however, determined to improve on some initially disappointing results, and worked hard to secure some top assignment marks in the New Year.

105. Passing his driving test and having access to a car (via Motability) increased my brother's independence. More significantly, it was less of a drain on his energy reserves than walking or using public transport, so he was able to attend academic institutions and succeed for longer than may have been possible otherwise. We did not possess a car before this point. My mother learnt to drive at the same time as my brother so she could drive him when his health declined.

106. I also secured good GCSEs and attained four A Levels, despite my Gran dying at the start of my examinations and my brother being in his final difficult months.

107. I felt that I functioned at school reasonably normally and largely kept my emotions in check. There was one occasion when I was overwhelmed however, so walked out of school to break down into floods of tears with my mother once I arrived home. I believed that staff did not know what was going on but, unbeknown to me, my mother had spoken to key teachers who remained discretely supportive throughout.

108. The same was true with my work colleagues. I was lucky never to have anyone pry or ask questions. They were flexible and understanding, especially when my brother was in his final days and I needed to leave work early or could not work as initially scheduled.

Section 6. Treatment/Care/Support

109. I am not aware of any difficulties my brother faced in receiving treatment, but he did make his own choices about whether to accept what was offered or not.

110. My mother has had difficulty regarding treating her Hepatitis C. At some point following her diagnosis, she received a letter from the Haemophilia Centre suggesting her Non-A/Non-B Hepatitis would clear up within a matter of weeks.

111. She also recalls the cost of Interferon based treatment being suggested as a limiting factor in her treatment options. As she suffers from Clinical Depression, even once the medics had put the financial qualms aside, she has not been able to undertake the treatment for Hepatitis C, for fear of the possible psychological side effects. She also worries that, even if she did have the treatment, it may fail and therefore be a waste of valuable NHS funds.

112. Haemophilia Centre social workers would visit our home for tea and a chat with my mother in particular. She was a stay-at-home mum so at home every day with my brother and I while my father was at work. Such visits occurred throughout my childhood and early teens. Both of my parents also met with them at the hospital for support too.

113. I met with a Haemophilia Centre Social Worker during my late-teens to discuss my feelings and our family situation. I presume the Haemophilia Centre suggested these sessions to my parents, as I did not ask for such support myself. I did not fully consider the purpose or benefit of such meetings at the time, although I did find engaging with such a warm, understanding and different perspective beneficial. This introduction to talking through issues with another was helpful to me in the longer term too, as it gave me the confidence to access counselling in the future.

114. My brother never availed himself of similar support systems although they would have been available to him at the time.

Section 7. Financial Assistance

115. As a minor I was not party to any financial decisions made at that time. My mother later informed me that they accepted statutory payments from the government, for all who had been infected via the Macfarlane Trust.

116. The Trust contacted my parents, highlighting that they had been awarded approximately £20,000 in compensation for infection. Therefore no application process was required.

117. No preconditions were imposed.

118. My mother thinks that the Macfarlane Trust may also have provided something towards our family trip to Florida.

119. My mother has a letter highlighting that if the infected died, they would not be able to access ex-gratia payments anymore. This has now changed, and has been applied for.

120. My mother now gets payments for having Hepatitis C. The National Infected Blood Scheme, knowing that she was infected, would have contacted her. She then had to apply to get what was available.

121. Her doctor would like her to apply for the Discretionary Fund, but she feels unable to do this. Trying to explain the psychological impact of Hepatitis C and, in her words, 'justify why she is ill', rather than present the physical impact alone is too much to ask, as it is too hard to do.

Section 8. Other Issues

122. I can provide a transcript (46 A4 page document) of my brother's treatment record. This covers each year, day and month of treatment, treatment product name, quantity (bottles used per treatment and amount per bottle), batch numbers and additional information e.g. significant Haemophilia Centre communications.

123. My mother also retains some letters. One for instance relating to a future child being no more affected than her. She has another from the Department of Haematology relating to test results. It indicates her already known abnormal liver function test and the only other problem being Non-A/Non-B Hepatitis, which *should go away in time*. This letter also suggests her urine should be tested fortnightly but this was not done.

Statement of Truth

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

Signed GRO-B

Dated 28th February 2019