Witness Name: GRO-B
Statement No: WITN3772001
Exhibits: WITN3772002 - 3
Dated: 15th January 2020

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 31st October 2019.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1937 and I live in Edinburgh, Scotland. My full address is known to the Inquiry. I am a widow and so I live alone. I am the mother of three children, GRO-B, GRO-B: S1 and GRO-B: S2, who were born in 1960, 1961 and 1962 respectively. I am also a grandmother, a great-grandmother and a great-great-grandmother.

2. I intend to speak first about my son S1' infection with Hepatitis C (HCV), and then I will speak about my son S2's infection with HIV and his untimely sad death as a result of that infection.

3. In particular, I intend to discuss the nature of my sons' illnesses, how the illnesses affected them, the treatment they received and the impact it had on our family.

4. My memory has been impacted by the amount of time that has passed since these events first occurred, and so I cannot recall dates and names as well as I once could.

5. I am not legally represented, I am happy for the Inquiry team investigators to assist me with my statement.

6. I request full anonymity.

Section 2. How Affected

S1

7. I married my husband, GRO-B in GRO-B when I was GRO-B, we were very happy and GRO-B years later we had our first child GRO-B in 1960. Soon after I gave birth to S1 in 1961 and S2 in 1962.

8. Both S1 and S2 are haemophiliacs. We first found out that S1 was a haemophiliac when he was about nine months old and he bit his lip while in his pram and it wouldn't stop bleeding. He wouldn't stop crying and so we took him to the hospital. The doctor told us that it wouldn't stop bleeding unless he stopped crying and said to take him home and give him half of an aspirin, which only made things worse, the aspirin thinned his blood.

9. We took him back to the hospital and that's when they asked if there was any bleeding in the family, when I said that there was S1 was then tested and they confirmed that he was a haemophiliac.

10. I was aware of haemophiliacs, who were called 'bleeders' as I had grown up around them and we had to be careful. All three of my uncles

were known as 'bleeders' and my Mam and Granny were carriers, but I didn't know that I was until after the birth of my third child, S2.

11. I didn't know much about haemophilia, back in the day it was never mentioned and we didn't discuss it, it was very much hidden under cover. I didn't know if my family had severe or moderate haemophilia because of this and I knew very little about treatment because there wasn't any. I would be told to look for cobwebs to stop the bleeding for my uncles or they would have to have a blood transfusion.

12. I was used to seeing bleeds and seeing my uncles in pain, but it is completely different when it is your child and you have to see them bleed and see them cry in pain.

13. S1 was ill a lot of times when he was growing up, when he was learning to walk his whole body filled with blood. He suffered a lot from internal bleeding, particularly from kidney bleeding. He had to be put on beds of sand and then beds of ice to get it to stop.

14. He was a very boisterous little boy, but his joints were bad. He would be out playing and he would hurt his knees but he wouldn't tell anyone. He ended up spending more time at hospital than at school, and primary schools wouldn't take him on in case he got hurt. He had to go to a school for disabled children eventually but he learned quite a lot there.

15. Whenever S1 had a bleed, the treatment was always a blood transfusion. Then they told us that he could use cryoprecipitate. It had to be administered at the hospital and it was done in the same way as the blood transfusions. I had to go with him any time he needed to have cryoprecipitate because he reacted so badly to it. He would have strong heart palpitations every time he received the cryoprecipitate and it would take an hour and half to give it him because of his reactions.

16. When S1 was about nine years old, the Haematology Department at the Western General Hospital said they had something new for us called Factor VIII. They told us that this would be a lot easier than cryoprecipitate because S1 could make the Factor VIII up himself.

17. He still had heart palpitations in the beginning but they eventually went away. S1 needed the Factor VIII when he had a bleed so it could be once a day or five times a day. He always tried to administer it himself but whenever he couldn't, I would make it up and give it to him. Both S1 and S2 used Factor VIII from then on.

18. We were always told that we shouldn't worry about anything for Factor VIII as all the blood had been given by Scottish donors. They said that we shouldn't use Factor VIII from anywhere else because all the donors from Scotland had been checked. If we ever visited England and needed it then they said they would deliver the Scottish product and that we should not use the English product. This was very much the general understanding at the time and it didn't bother us as we had no intention of going anywhere without the Factor VIII.

19. In 1990, S1 was told that he had a foreign body in his blood. He continued to take Factor VIII and had a routine blood test but he was concerned about the foreign body that they had found. He was always complaining about sweating and being tired all the time at this point. He never wanted to dwell on it but you could see that he was very very tired. Eventually, he went to see a liver specialist who told him that he had HCV.

20. I know that S1 found this news hard to take, he became very quiet and distant, especially as his brother was so sick at the time as well. I know he didn't want to upset people more so he kept to himself and suffered in silence. It must have been very difficult for him.

21. They scanned his liver after originally intending to give him a liver biopsy but they stopped doing those before his was due, thankfully he

didn't have any cirrhosis. Shortly after his diagnosis, they put him on Interferon treatment.

22. They treated him very poorly and didn't tell him the right way to take the Interferon, and they only gave him the injection. He was living alone in his flat and was injecting himself in the stomach once a day every day and he was not in a good place. He was very confused all of the time, he was always feeling sick, he kept saying that his head was about to burst and he was more tired that ever. He kept saying that he had to stop taking it but he didn't, he wanted to get better. I had to visit him a lot to take care of him.

23. One night he rang me and said that he couldn't take it anymore, his head was bursting and that he was trying to get out of the front door because he was feeling like killing himself. I managed to talk him round and convinced him to take two painkiller tablets and to go to sleep.

24. When he woke up he said he was going to be sick and that his head was still bursting. After that we went to see his doctor and found out that he should have been given a tablet to go with the Interferon injection. He was in a very bad place and he didn't want to talk about it so he decided to stop the treatment there, after two weeks on it.

25. S1 had to be put on anti-depressants because of how low the Interferon had made him. I was worried that he would do something stupid to himself like taking an overdose of something.

26. About five or six years later, S1 was asked if he wanted to go back on the treatment but he said no. They said that they would give him a tablet with the treatment but even S1' specialist said no.

27. Eventually, he was given several tablets to take together to try to clear the HCV. He was very low and very ill while he was on the tablets but not as much as he had been when he was Interferon. He couldn't eat and he said he felt like he had the flu or a virus of some kind.

28. One time when I went to see him, I could see that he was bloodless, just by looking at him I knew that he was bleeding somewhere. He was going to the toilet a lot as well so I knew he was passing blood somewhere.

29. I managed to get him to Raigmore Hospital in Inverness where we found that he had lost five pints of blood. He had a stomach ulcer which they think was because of all the tablets he was taking for the HCV. He stopped them that week.

30. The new tablets obviously worked and he was told about two or three years ago that he was clear of HCV.

31. S1' health is a lot better than it was and he is much more himself now. He has regular check-ups following his HCV free result. His joints are also good for what he has been through but his bones are thin and his ankles are his weakest point. He would shout at us not to come near him as he was worried that we would touch him and he would be in pain.

32. He lives a very healthy life and hasn't had drink in many years now. His mental attitude is much better, he used to be very distant and he is now communicating with family and has opened up a lot.

33. S1 did well considering what he had been through but he felt very guilty about how much his brother, S2, suffered.

S2

34. S2 was the youngest of my three children. He was a very good baby and rarely cried. S2 was quite pale when he was born so I asked for him to be tested for haemophilia. The hospital said they wouldn't test him because you don't have two sons one after the other who are so close in age and are both haemophiliacs. They also told me

that the first son is never a haemophiliac. They were wrong on both counts.

35. When my Granny saw S2, she told me to get him tested because she could see that he was a haemophiliac. She had three boys who were all haemophiliacs and she just knew that he was the same. The hospital still didn't want to test him when we went back, telling us that it would take too much blood from him and that it was too much to put such a young child through.

36. Eventually they did test him and then they claimed that the blood was too cold when they received it to test it. They tried to talk me out of it again but I was determined and he was tested again. He was confirmed to be a haemophiliac at about three months old.

37. After S2 was diagnosed, the hospital told me that I was a carrier. This is the first time I was told, I had no idea until that moment. They also told me that I shouldn't have any more children to reduce the risk of having another haemophiliac child.

38. There was no evidence of bleeding with S2 but he was always pale and weak, and you could tell that he was more delicate than the rest. He didn't have many bruises but he always broke something and was in and out of hospital, but he was only in for days not weeks at a time like S1 had been.

39. When S2 was a year old, he had a brain haemorrhage. He had to have a brain operation from eleven o'clock at night to six o'clock in the morning. It was very scary. They told us that he would survive but that he wouldn't be able to walk or talk or do anything.

40. The hospital said that we should put him in a home instead of taking him back with us. I said no and brought him home and he started to push a chair around and then started walking at the same time as the other children his age.

41. He had a lot of injuries when he was young, he broke his thigh bone once and a teacher had to come to the house to teach him. As I said earlier he also suffered from a brain haemorrhage but the school wouldn't take him back until it was certain that his brain was clear of the haemorrhage. Thankfully it did clear but it lasted for a year and he missed out on a lot.

42. The boys weren't allowed to go out to play as much as other children as we were scared of them getting hurt. Both S2 and S1 spent a long time in hospital for various breaks and fractures and bleeds, and we wanted to limit those visits as much as we could. S2 broke his thigh-bone and then he did it again and was in the GRO-B Hospital for a year.

43. It was very difficult for my husband and I to have our boys away for such a long time and to see our sons bleeding and in pain and in traction because they've broken another bone. It's hard when people ask about stories when they first started walking or talking because I can't tell them, we weren't there to see it happen because they were in hospital.

44. S2 didn't let his haemophilia hold him back in any way, he was very very stubborn. He was always right, especially about the Rangers to the point where he would get on the phone with the manager. There was one time when he was playing with marbles with his friends and some older boys tried to take them. He came away grinning with a bloody nose and his marbles, even though I had to rush him to hospital where he had to spend the night.

45. He used that stubbornness and determination to get himself to college. He was refused a grant in GRO-B as he had barely been at school, so he moved in with his Auntie in Edinburgh so that he could go to college there. He didn't want to tell people why he hadn't been at school but the principal of the college told him that he wouldn't get a

grant unless he did. He was determined to go so he told them and he got a grant and enrolled in college.

46. In spite of everything, S2 did well at college and he then began training to be a lab assistant. In 1983, he went to the Royal Infirmary, Hospital, Edinburgh to have his routine six-month blood test and everything came back fine. When he went back six months later, in 1984, to have another blood test and to find out the results of the last test. When he got there, the haematology doctors from the Royal Infirmary told him that he was HIV positive and that he had ten years to live.

47. He was in complete shock. He went down there to get good results. He was completely devastated. From then on, he was a different person, he was never able to get over it.

48. He didn't tell us what happened straight away but we knew that something had happened. My daughter went to see him and came back saying that something was wrong with S2 that he wasn't himself. I wrote a letter to him and my husband went to see him and he said the same as my daughter. S2 wouldn't talk to them but it was clear that he was ill and not himself. It must have been very difficult for him to be alone and away from his family and hiding this terrible life-changing news from us. It must have been so scary for him.

49. I decided that I couldn't let my son be alone when something was so clearly wrong and I needed to be in Edinburgh with him. So, in October 1985, my husband and I sold our house and moved down to Edinburgh to be with him, not knowing what would happen when we got there. We moved into his flat with him until we found a house. I think all of us being there when he hadn't told us what was going on must have been difficult for him.

50. One night, after we had been living there for a few weeks, he told me about his check-up, that he was HIV positive and that he had been

given ten years to live. It was the last thing a mother wants to hear. It was terrifying.

51. It must have been several months from when he found out to him telling me. That's a long time to carry that secret. S2 didn't want me to tell anyone else and he told me that he hadn't told his Dad in case he told his side of the family because he was worried that they wouldn't accept him and that they would judge him. He was very worried about the stigma surrounding HIV. He didn't want his sister to know either as he didn't want her husband to find out in case he would keep the children away from him. He must have felt terrible facing all these fears.

52. I had to keep S2's diagnosis a secret for about six months but I had to tell my husband in the end and I told him that he couldn't tell his family. Eventually he told his brother and sister one day when I was out of the flat. GRO-B told her husband and he said he wouldn't keep the children away. S2 was really terrified of what would happen.

53. We eventually moved out of S2's flat, he cheered up but he was still very sick and I continued to care for him. One night, in the late 1980s, S2 was very sick. He was coughing a lot and vomiting, he wouldn't let anyone in to see him and he wouldn't let me take him to the hospital. I managed to get him to hospital in the middle of the night and they told me that they would keep him there for a week and that I should have a week of respite. I decided to go GRO-B for week and after the first day, S2 collapsed in hospital and I had to come back. It was a brain tumour and the start of full blown AIDs.

54. After the brain tumour was discovered, he developed leukaemia but it was different to the big, black cancerous sores the drug addicts were developing, it wasn't obvious. You didn't see any evidence of HIV when you looked at S2, you would never know from just looking at him. It was only as he reached the end of his life that S2 did become gaunt and skinny.

55. S2 wasn't given treatment to try to help with the HIV but he was given AZT tablets. These didn't help him and he didn't react well to them at all. They made him anaemic and he was losing blood as well as making him feel very low. He had thought about stopping and then when his GP told him to come off the tablets as they weren't doing him any good, it was a relief and he stopped.

56. He did have some good times in the last fifteen months of his life, when he was bedridden. Some days he would argue with his sister and the next day they would be back to normal, just like any brother and sister do. When his Dad and his brother were there, they would talk all day, they were just happy to be able to spend time together.

57. I always wanted to take care of S2 myself. The hospital treated him very badly, I will talk about this in detail later in my statement, and I wanted to bring him home. I was going to see him every day to feed and wash him anyway so it seemed to be the best thing to do. The hospital said that I couldn't take him, that it would be too much for me but I told them that I would manage and I brought S2 home.

58. Towards the end of his life, S2 was only on painkillers and had to take liquid diamorphine. S2 was never a fan of sweets but he was eating a carton of ice cream a day because that was about all he could manage.

59. S2 passed away at home, where he wanted to be, at twenty-nine years old on GRO-B 1992. I was with him all day. In the afternoon, my daughter went downstairs to make us a cup of tea and I stayed upstairs with S2. He wrote on a piece of paper that he loved me, to say my prayers and to forgive the nurses for the bad way they had treated him and that I should go get my tea. When I did, my daughter noticed the silence from his room so we went back up and he had passed. I know that he told me to go downstairs on purpose.

60. He looked at peace, he was relaxed and calm and he was ready to go. I felt relief when he passed because I knew my son was at peace and finally free from the pain.

Section 3. Other Infections

61. I am not aware of S1 having received any infection other than HCV, and I am not aware of S2 having received any infection other than HIV.

Section 4. Consent

62. S2 was tested for HIV without his knowledge and without his consent, because of this he may have been tested for other infections or illnesses without his knowledge or consent.

63. As far as I'm aware, S1 consented to all tests and treatments and was not tested or treated without his knowledge or consent.

64. As children I consented to their treatment.

Section 5. Impact

65. My sons' infections had a tremendous impact on both of them and their lives as well as the lives of the rest of our family.

66. S1' health is a lot better but now but he suffered a lot mentally from both his brother's and his own infection. He used to be angry about what had happened to him and his brother, he was angry that they were taking something that was supposed to keep them alive but ended up killing them. He has now accepted what happened but he suffered for a long time.

67. Before S1 knew about his HCV diagnosis, he was very upset and he felt guilty that S2 was suffering. He used to say that he drank and smoked but was fine but his little brother didn't do any of that was lying there with ten years left to live. I know he struggled a lot with that guilt.

68. When S1 found out that he had a foreign body in his blood, he told me not to tell anyone as S2 was already very sick because of the HIV and he didn't want to upset anyone, especially his brother. When he found out that it was HCV he became very quiet.

69. S1 found it difficult to visit S2 in hospital. They were very close and they more like twins than just brothers, they had a very strong bond. I was hard journey for S1 to do to get to the hospital and it was not easy for him to see his brother so ill. He was always aware that it could be him lying where S2 was. He doesn't talk about S2 anymore to us, he says he speaks with his brother on his own and in private.

70. S2's death and S1' infection had a big impact on my daughter, GRO-B, she was affected very badly by everything. When the children were younger, my daughter had to grow up quickly because a lot of our life was spent travelling back and forth from hospital. When I had to go to hospital to see one of them or rush them in for treatment, GRO-B had to look after her other brother. She was very good with her brothers and unfortunately; I had to depend on her a lot. I wasn't happy with this but there wasn't another choice because of how often the boys needed treatment. The strong relationship she had with her brothers made it very difficult for her when they both got sick.

71. I think S2's death was made worse for GRO-B by the shock of her father dying before S2. She didn't believe me when I told her; she said over and over again 'no it's S2 who is sick, not Dad'. She is very anxious and she has had panic attacks ever since they both

passed away. My husband dropped down dead in front of me when he was making a cup of tea. This was as a result of a huge heart attack.

72. I know that GRO-B is still angry about what happened to her brothers and how it would even happen. She still won't talk about it or even mention it. None of us have been offered counselling but I think that GRO-B is now looking into that for herself.

73. GRO-B is a carrier for haemophilia and her daughter is a carrier and a borderline haemophiliac but she doesn't need Factor VIII. I think this must be scary for GRO-B after having to watch what her brothers suffer after receiving contaminated blood.

74. The HIV diagnosis changed S2, he developed OCD quickly after he was diagnosed. He didn't allow anyone to get near him as he was so frightened that he would give HIV to one us. He would watch our every move when we would leave the room to make sure that we washed our hands and would send us back if he didn't see us do it. He would wash his own hands thousands of times and everything had to be done in sets of three. It confused the children as they didn't understand why they were allowed to touch him before but now he wouldn't let them.

75. S2 stopped talking and started communicating by writing things down instead because he was worried that he would infect one us with HIV through spit or air. He was silent for two and a half years. You would only hear him speak if he was angry which he was at the beginning after the diagnosis.

76. Everything that he touched started to disappear, if he came over to our house then you couldn't find the fork he used or the glass he drank from, he was trying to protect us in every way possible. I once asked him to bring a headboard home with him and he said he would but when he came home he didn't have the headboard. S2 always

cared about the family more than himself, and this was another way he did that.

77. S2 used to ask me a lot of the time if I thought that he would live another ten years. I tried to reassure him that he had every chance because he lived a healthy life, I didn't know what the future would be like for my son but I wanted to give him every comfort I could. I always looked after him the best I could and gave him all that I could.

78. When S2 came out of hospital for the last time, he asked me to ring the hospice for him to find out how one of his friends was, and I had to tell him that his friend had died. I was afraid to do so especially when he asked me if others were gone too and I had to say yes. He cried very sorely and said that he would be next.

79. Before S2 died, a gay man informed the hospital that he donated blood and has since been diagnosed with HIV but that he did not know he was positive when he donated. They traced his donation to the batch that S2 received and so he was told about what had happened. S2 didn't say much about it, only that it was not the man's fault.

80. One day I asked him how he felt about what had happened, and he said that he wasn't angry anymore and that he had come to terms with it. He had injected himself with contaminated blood product and that wasn't anyone's fault.

81. S2 had accepted what was going to happen to him and got himself ready to die. He wasn't scared, he had spent a lot of time praying and he was happy and at peace. I am glad that my son did not die scared or upset, and that he went peacefully. I am grateful that he had his faith as I do not know if he would have coped in the same way without it.

82. As a mother, it was very difficult to see your children bleed so much and cry out of so much pain, but having to watch both of my boys fight

such terrible infections, and to lose one, was heart-breaking. My life was changed completely.

83. I had to hold a lot back from my family during both of my sons' illnesses. I had to promise not to tell anyone about S2's HIV and then S1' HCV. It was particularly difficult not being able to talk about S2 as we were all living in a small flat and I was living a lie.

84. I lied to everyone for six months, I couldn't even tell my husband, I felt overwhelmed by everything. They were aware that I knew something. They would say that I was protecting him as he was the baby of the family not knowing what he was going through or the intense fear of rejection that he had.

85. While we were staying with S2 in Edinburgh, I started to feel everything was getting on top of me and I was struggling emotionally. I felt a lot of pressure because I wasn't able to talk to my husband about S2's infection at this time. I hated not being able to talk to him, I didn't like hiding it from him and I needed to talk about what was happening to help me cope. It was at this point that I started to drink cans of Carlsberg Special Brew to help me cope. I soon realised that this was a false way of managing my emotions; I stopped drinking and relied on my faith. I also sought medical help.

86. I was frightened for my son but I knew I couldn't tell anyone, I still feel that way as there some people I can't tell even now. As a family, we had to keep very quiet about what happened.

87. S2 was very worried about stigma and so heavily limited the people we told about his infection. There are still some members of our family who don't know about it even now, and that is one of the main reasons why I am asking for anonymity.

88. S2 was so worried about the stigma of HIV that he didn't even want me going to the counselling centre in case someone found out. I remember a day shortly before he died, I went to the chemist to get the diamorphine and he wrote on a piece of paper "please tell the doctor that I'm not a heroin addict".

89. We found S2's death particularly difficult as my husband passed away six months before he did. I didn't have him there to talk to about what was happening to our son. It was made even harder by the fact that S2's death divided our family. We all processed it in a different ways so it was very hard to process it together.

90. I had lost two of the most important people in my life and I couldn't talk about it. I wasn't offered counselling so I wrote everything down instead, it was the only way I could cope. It was a relatively new thing to happen and I know that some haemophiliacs didn't cope with it well.

91. I wrote a piece for the Scotsman using pseudonyms titled 'Ewan's Story' published on 25th November 1995. I wrote contributions for a collection of personal stories of HIV and AIDS called 'Colours of hope and promise' as well as a short piece for a collection called **'Voices – Writing from Solas and Milestone'**. I include my contribution here: You will note that the names of my children have been changed.

"James was born on GRO-B 1962, the second son and youngest of three. He was a good baby, never any bother, rarely crying. In fact the nurse used to come in to make him cry during the first week of his life. She called this 'exercising his lungs'.

From the first James seemed different in a special sort of way, always pale and delicate looking. As his brother was a haemophiliac, I asked the doctor if he thought it possible that James could have the disease. He said no, as they were so close in age. However, when James was a couple of months old the doctor at the hospital did agree to test him.

He wasn't too happy about it as it involved taking blood. He thought it was a lot to put a young child through. Unfortunately the test didn't work the first time and a week later we had to go through it all again. This time the results were positive, but the hospital thought he had a mild form.

Haemophilia is a blood disorder where the normal clotting factor is missing, making the smallest cut or bruise a major worry. You can imagine, with two haemophiliac children in the family we were always kept in our toes. They were quite boisterous and of course this was in the sixties and we didn't have the modern drugs available nowadays. They were in and out of hospital like nobody's business. In fact, more in than out.

Because it had always been in my family I knew all about it. In a sense I was used to all the bleeding and crying with pain. But you never get used to seeing a child of yours screaming with pain, filling three milk bottles with blood whilst bleeding from the kidneys. Or seeing the other one in traction for months after breaking his leg in a couple of places. My husband had never heard of haemophilia so he probably found it more difficult at the beginning.

When the boys were young they didn't really get out to play a lot for fear of them getting hurt. As they got older they wanted to be the same as their pals and started to go out more. Some kids were good at looking out for them but there was the odd cruel one who would throw stones at them just to make them bleed. But, by God, they would hold their own. One summer holiday James was playing with his friends when three or four older boys came along and tried to take their marbles off them. He came rushing into the kitchen with a bloody nose. I had to leave everything and rush him into the hospital. He was still grinning and clutching his marbles. He didn't care that he had to spend the night in hospital – all that mattered was winning the fight.

In the early 1980's we moved to GRO-B *with our three children, James, Michael and Eileen. One August James left home to go to college in Edinburgh. Things worked out fine for a while. He was studying hard and his first set of exams were getting closer. Unfortunately there wasn't much room at his uncle's house and things started to get difficult. Eventually James decided to move to a bedsit, but this didn't solve his problems either. As he was a haemophiliac he had to inject himself regularly with Factor V111 (sic) which has to be stored in a fridge. He had to move a couple of times because of strict regulations which closed the kitchen at eight o'clock in the evening. Who was to say that James wouldn't need an injection in the middle of the night? He had to have 24 hour access. He also worried about drug addicts breaking into hid (sic) room looking for needles. All in all it added up to a pretty stressful time.*

In spite ofthe (sic) hassles he was doing well at college and had passed exams in biology and chemistry. He was training to be a laboratory assistant. In December 1983 he went. For his regular six monthly check up for his blood count. It was fine. Six months, however, he was tested for the HIV virus without his knowledge. You can imagine what a terrible shock it was when he was told that he was positive. It was completely devastating and I don't think he ever really got over it.

From the day he was diagnosed he was a changed person. The possibility of infecting someone he loved worried him constantly. He got very careful about injecting himself with factor V111 (sic) and was always washing and bathing. We used to tease him a lot because we used to have to queue for the bathroom. He was terrified and became very deep. You could never figure out what he was thinking.

Very often he would ask me if I thought he would live another ten years. I tried to reassure him that he had every chance because he lived such a healthy life.

I don't think any of us realised how much he suffered in silence. At first he didn't tell anyone of the diagnosis. It must have been terrible for him all alone in a s strange city keeping the news to himself. I soon began to suspect that he was hiding something from us. I'd always been able to tell when something was wrong. I could tell from the letters and the phone calls that despite some good news about a flat, something was still not right. Then suddenly one night on the phone it all came out. He told me he had the virus and that it would kill him. He made me promise not to tell anyone, not even his father. It was very difficult for me to pretend everything was fine.

I then made up my mind that I was going to move to. Edinburgh to be with him. My husband agreed. It was too hard for us to think of James trying to cope with this on his own. It was a big decision for us to make. We were giving up a good house and weren't sure what was in front of us.

We moved down in October 1985. Things were very difficult. The flat was small for three people. The worst thing was the isolation. James didn't want me to tell anyone that he was HIV positive so I had no one to talk to about my worries and fears. He didn't want his sister to know as he was frightened she would stay away because of her small children. He wanted to tell his brother himself.

I went to the hospital to try and get as much information as possible on AIDS. I wanted to find out anything that would help me cope with James as he got ill and to know how to protect myself. About this time he did tell his brother and sister of his diagnosis, but not his father.

With the flat being so small, everybody was getting on each other's nerves. I started to sell off furniture to make more room. I began to fell (sic) everything getting on top of me, the situation was so difficult. Soon

I was drinking heavily again, even though I knew it would only make things worse.

Over the years I'd come increasingly to rely on drink as a way of dealing with the stress. It had been a hard time bringing up the family with my husband mostly out of work. I'd sometimes be able to find the odd part time job but they never lasted. One of the boys would always get hurt or have a bleeding and I'd have to leave work to look after them. As my husband had a problem with gambling he couldn't be relied upon to take over at home. My daughter was very good with her brothers and I depended on her a lot. I wasn't happy about this as it stopped her spending time with her friends. I didn't want her growing up with an old head on young shoulders, but what choice did I have?
It was the only way of life we knew.

I was hardly ever able to get out in the evenings so my neighbours took to popping in with a drink. Before I'd never been much of a drinker but now I began to find it a comfort. Having the odd drink made everything seem easier and for a while I'd feel good. Some weekends when my husband went to the dog track I would buy myself some drink and sit alone with the curtains closed, secretly and silently consoling myself. At the time I didn't realise the alcohol was making me more and more depressed.

When we moved up North our life had improved. We had a nice house, the boys had more space and freedom and had settled down well at the new school. My husband cut down on his gambling and I tried to stop drinking with some success, although I still depended on it at the weekends. When we moved to Edinburgh the pressure started building up again and I turned back to drink. As no one was working we were very short of cash. We were always fighting about lack of space and money. James refused to let me tell his father he was HIV positive. I was getting no counselling or help of any kind as James didn't want me to go to the counselling centre.

Then, one afternoon when I was in the flat something extraordinary happened. It's really hard to describe. I hadn't been thinking of anything in particular, just sitting on the couch. It was November, a bleak wintry day with spiteful gusts of sleet laden wind. It was only three o'clock but already dusk was falling, filling the corners of the room with darkness. Outside pavements glistened with dampness, silently absorbing the last of the heavy light. I'd been out shopping earlier and bags still lay where I'd dropped them. With a heavy sigh I kicked off my shoes, wriggling my toes around in my tights.

I'd have to get up and take the messages to the kitchen before the frozen things defrosted but just now, just for a moment, I was going to sit here and do nothing. I lifted the red and white carrier bag containing two bottles of sherry onto the cushions beside me and cradled it against me leg. They made a familiar, comforting chinking sound. Soon it would time to open one and have my first drink of the day. it (sic) was getting earlier and earlier. Yesterday I'd promised myself, I'd hold out 'till four o'clock but I knew I'd never make it. Inside my head I began the familiar litany of self justification, "Oh well, it won't hurt, just this once. I've had a hard day, I deserve it. I'll make up for it tomorrow. Tomorrow I won't have a drink until after tea……."

I stopped abruptly, aware for the first time of the texture of the carpet beneath my feet. It felt cool and as soft as grass. A delicious feeling of warmth slowly crept up my tired legs. My knotted limbs began to relax and unwind until I felt as though I was dissolving into the couch. Closing my eyes, somewhere between dreaming and waking, I saw myself walking across a vast meadow surrounded by flowers, above me an arch of birds, their brightly coloured throats vibrating with song. A tear splashed down onto my hand. For the first time I was crying for myself.

I always looked after James the best I could and gave him all the comfort and love I ha. One day when he was on good form I asked him *how he felt about what had happened to him, if he was angry or bitter because of the way he'd been infected, angry with life. He said he wasn't anymore, that he'd come to terms with it. He'd injected himself with the contaminated blood and it wasn't anyone's fault. He'd got over his fear and was happy and at peace. He spent a lot of time praying and I do think he'd make peace with God…..*

During the fifteen months he was bedridden it was not all gloom. We laughed a lot and he had funny days. He had some good times with a couple of the hospital nurses who had got to know him well before he got ill. Sometimes he did nothing but argue with his sister but other days they got on fine, just like any family. Often he told me that she was mad! Michael came at the weekends if he could manage it; it wasn't easy for him to travel, not easy to see James so ill. They were so close, more like twins than brothers. I think he was always aware that it could have been him lying there. James was always happy to se (sic) his Dad but when the three of them got together they did nothing but talk about racing and football. Things could get very hectic because none of them ever agreed on any one thing, but at the end of the day they were happy to spend time together.

In December 1991 James came out of hospital for the last time. He told me he wanted all of his tablets stopped except for the painkillers. One day he asked me to phone the hospice to find out how one of his friends was. I'd always been afraid to tell him that any of his friends had died, but now I had to say yes. He cried very sorely and and (sic) told me that he was going to be next. In the end though I felt relief when he died. He was free from his hell and at peace."

92. I produce a scanned copy of this booklet as my exhibit **WITN3772002**. Despite trying to hide the identity of my family, some people still knew that it was us. You will note that there are entries in the text that

indicate that I was hiding bottles around the home, this is incorrect and my story was confused with someone else's.

93. It would be fair to say that I was drinking more than I would normally to the extent of dependence but not to the extremes recalled in the above passage from the booklet.

94. I am not happy about what happened at all but I do believe that that it was meant to happen this way, and I see it as a challenge that was put out for me to see how I would handle it, I believe it was a test of my faith. I think that I have managed to cope well considering what I had to go through.

Section 6. Treatment/Care/Support

95. As I mentioned earlier in my statement, when S1 went on the Interferon treatment to try to clear the HCV, he was only given half of the treatment and he wasn't even shown how to administer the treatment they did give him. S1 suffered a lot and unnecessarily because of this mistake. He only spent two weeks on the treatment and he was having suicidal thoughts and had extremely painful headaches.

96. I was so worried about what might happen to him while he was injecting himself with Interferon. That treatment almost killed him and no one noticed the mistake until we went to see a different doctor. It is painful to think about what would have happened if he had carried on with the injections.

97. S2 was treated very badly in hospital. S2 would go into trances and have seizures because of his OCD. I tried to get him help from the hospital but no one would listen to me. They said that he was just spoilt, I tried and tried to convince someone that he wasn't putting

it on but I couldn't get through to anyone. There were so many times when S2's life could have been made easier and better if someone had just listened to what was happening instead of just dismissing it.

98. The hospital also wanted to get rid of the haemophilia ward and put all of the patients with blood disorders on one ward. They were moving them all during the week I was supposed to go on respite. S2 really didn't want to go, the only thing that gave me some comfort leaving him in hospital was that one of the sisters on the original ward said she would look after him and that she would take him back if he wasn't happy. She stopped anyone looking after him but instead left him completely drugged up when he couldn't feed himself. My family called me saying how unhappy he was and so I came to see him and I found him in cot, like an animal in the corner. It was horrible.

99. I asked to see a doctor but I was told that it was midnight and all of the doctors were busy. I had the head of haematology's number and so I phoned him to ask why S2 had not been seen by the doctors. He said that he didn't know that S2 had a reason to see a doctor, and I told him that he did but that the hospital hadn't told him.

100. He came up the next morning and he was so shocked. I wanted to take S2 home with me then and there but he convinced me to let them keep him for a week. I went to see him in hospital every day to feed him and wash him because the staff weren't doing it. After that I took him home so that he could be comfortable and around people who loved and cared for him.

101. We had been told by the hospital not to tell the undertakers that S2 had AIDS, we should only tell them if they asked. After S2 had passed, the undertakers came to the door and said that they needed to take him now because he had AIDS. I asked them who told them and they said that it was the Minister. Before S2 passed, our

minister, GRO-B would often come to visit him, and when we found out that he told the undertakers we felt very betrayed.

102. I asked the undertakers, GRO-D, to leave him so that his brother could say his goodbyes and that he was on his way and wouldn't be long. They refused and just took my son away.

103. The hospital rang later to ask if S1 had been able to see his brother and I told them that they wouldn't let him because they knew about the AIDS. They asked how because S2 had no markings on his body that would show that he had AIDS so I told them. The hospital said that they would get them to open the casket, but I said just to leave it now. S1 never got to say goodbye to his brother and have that closure because of that minister.

104. I was told that when people had died of HIV before, they had put 'murder' as the cause of death on the death certificate but S2's certificate was more accurate and says that he died of bronchopneumonia, immunosuppression and haemophilia A and cerebral toxoplasmosis. I produce a copy of his death certificate as **WITN3777003.** Neither HIV or AIDS is mentioned on his certificate.

105. Once they took S2 away, we didn't have the opportunity to see him again. I thought this was the policy but I was later told that as he had no sores we should have been allowed to see him. It felt very bad that we couldn't see him one last time and say our goodbyes.

106. When the boys were diagnosed with haemophilia, the hospital didn't give me any safety warnings or guidance about how to care for haemophiliacs. I only knew how to handle it because of my family and I know that my husband found it difficult when they were very young.

107. I went to a meeting hosted by a psychologist who had been part of the team treating S2. She said that you should never make promises to someone who is dying, and it was like hearing my own

words being said to me. That is what she did, she did make promises, and that is what I said she shouldn't have done. I spoke to her afterwards and said 'you could never have helped my son' and she said that she couldn't help him. She should have said that then, not after he is gone.

108. I felt let down by the system when I found about both S1’ and S2’s infections. I thought that nothing would happen to my sons as they didn't use drugs, they weren't gay and we had been told that the blood had been tested. I thought that I didn't need to worry about them. We were even told that we shouldn't accept product from anywhere else. They told me that the blood was safe and that my children would be safe using it when it was the opposite.

109. I am not angry at the donor whose blood was infected, I am angry at the hospital for not testing it especially when they said that it was being tested.

110. I promised the haematology department that I wouldn't say anything about HCV and I wouldn't say names, even though they lied about the blood being from Scottish donors. It was found out that the department was taking blood from Americans and using it here.

Section 7. Financial Assistance

111. I am not aware of the exact details of how my children got financial assistance but I know that S1 received some money from the Skipton Fund.

112. I know that S2 got £20,000 from the MacFarlane Trust which he put into the family. My grandchildren still sleep in the beds that he bought for them.

113. Neither S1 or S2 had to sign anything to confirm that they would not bring any action against the NHS.

Section 8. Other Issues

114. I would like the Inquiry and my statement to help doctors to realise that they need to listen to their patients and the parents of their patients, and how important it is to do that. No one listened to me when I told them about S2's OCD or even his testing for haemophilia at the beginning. I felt completely unheard and everything that needed to happen was a battle I had to fight with the doctors to get done. You know you have asked for things and you have asked for help but they don't do it and they just say no. They say that listening is an important part of what they do but they don't do it.

115. I didn't provide a statement for the Penrose Inquiry but I am glad to be providing one now.

Statement of Truth

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

Signed GRO-B

Dated 15th January 2020.