Witness Name: Helen Martin
Statement No.: WITN0085001
Exhibits: Not Relevant
Dated: 13/9/19

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF HELEN LESLEY MARTIN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26 October 2018.

I, Helen Lesley Martin, will say as follows: -

1. Introduction

1. My name is Helen Lesley Martin. My date of birth is GRO-C 1961 and my address is known to the Inquiry. I am by training and 30 years working a primary school teacher. I am currently unemployed.

2. I am thanks to Human Inmmundeficiency Virus ("HIV") and Hepatitis C Virus ("HCV") bereaved of two brothers, one fiancé, four cousins and a number of family friends. A further family member was lost to suicide after the death of their father, I believe his sister will give evidence of this.

3. I intend to speak about my brothers, my fiancé, my family's loss, the effect of that loss over the subsequent years, the effect it has had on my health, my career and financial situation. In particular, the nature of their and my illness,

how the illness affected us, the treatment received and the impact it had on our lives together.

4. My younger brother: CHARLES DUNCAN MARTIN known as Duncan. Born GRO-C 1968, died 8 December 1986 aged 18 years.

5. My older brother : JAMES ALEXANDER MARTIN, known as Sandy. Born GRO-C GRO-C 1958, died 9 October NR aged 45 years.
2003 GRO-C

6. My fiancé : STEVEN JOHN ANDERSON, known as Steve. Born GRO-C 1957, died 16 March 1991 aged 34 years.

2. How Affected

7. The people close to me were: My elder brother, my younger brother and my fiancé, who withdrew his proposal of marriage as he felt it unfair, I should have to suffer his bereavement after having already lost my younger brother. I told him the decision was not really his and that the loss would be no less because I was not wearing a ring. It was a decision I had hoped in time to over turn but could not. As I knew it would be, the loss was no less for the absence of a ring.

8. They were infected by injecting Factor VIII and what happened to them is, that they are all now dead.

9. The family have also lost cousins and many family friends made through school and our membership of the Haemophilia Society.

10. My brothers both had severe Haemophilia A.

11. My fiancé likewise had Haemophilia but I do not know his level of severity. His mother maybe submitting evidence, I can enquire further if necessary.

12. My older brother, Sandy attended Lord Mayor Treloar College ("LMTC") from 1970 to 1976 and whilst there was infected with Hepatitis. I was young at the time. I do know that his crockery and cutlery were marked because of this. I doubt he was the only boy infected or marked out in this way. It is a strange memory to have all these years later.

13. At the time of being infected

14. with HIV both my brothers were being treated at St. James' Leeds. They were both registered at the hospital from shortly after their birth, treated there throughout their lives, and both died there.

15. The haematologists at the time were Doctor Swinburne and Mr McVerry. Who signed out the Factor VIII would depend on the circumstances and the time of day. Was it signed out to collect for home treatment and collected from Haematology, or had they gone to A&E in an emergency, in which case A&E would have to request it and have it sent down, so it could be administered.

16. I have not seen their medical records and do not know whether such information is contained within them.

17. My fiancé had also attended LMTC, lived in GRO-C in Oxfordshire and received treatment from hospital there. He later lived on the GRO-C and was registered and received treatment from the hospital in Inverness. At the time of his death he was living in GRO-C in Somerset. I do not know the hospital details or doctors' names but am sure his mother can detail this if needed.

18. My cousins were I believe registered at Bradford, again closer family members are providing evidence.

19. I cannot say when or for how long my brothers were treated with the contaminated blood products only that it was obviously before the tests. The results which came after GRO-C 1986. My younger brothers 18th birthday.

20. I do not know when my fiancé was infected, whilst in GRO-C or on GRO-C. But believe it was whilst on GRO-C being treated at Inverness that he was told he was infected.

21. At the time the proverbial hit the fan, the damage was done. We didn't ask "why didn't you warn us?" we assumed they hadn't known; only later did we begin to realise that they had knowingly opted for the high risk products. They may or may not have known about the HIV but this was high risk, "dirty blood". Collected as we now know, from prisoners, drug addicts, and infected donors. If the people responsible for making this choice say "but we didn't know" then I say they were not doing their job properly. At that level of purchasing power there must surely be an expectation to do your research and exercise a duty of care. They should have known who it was being sourced from and investigated what risks that involved. Even if HIV had not been identified at that time they can hardly claim it was a good source.

22. I do not recall my family being advised of the risk from blood products, though it would have meant little. "There is a risk you'll get this scary virus if you use factor VIII, there is a risk you'll die if the bleeding isn't treated." Factor VIII is not optional, it's not shall I shan't I. Should I take aspirin or paracetamol for my headache, it was until this time of infection, a lifesaving, life changing way of stopping bleeding.

23. When my older brother was little the treatment was transfusions of pint after pint of whole blood often requiring weeks in hospital until the bleeding stopped and the painful swelling went down. The transfusion of plasma, injections of Factor VIII and the coming of home treatment seemed nothing less than miraculous, Factor VIII was life changing.

24. My older brother as stated above had hepatitis whilst at LMTC, but no mention was made of it at the time of his final illness and death. No mention of HCV was ever made in relation to my younger brother, but HCV was a contributory factor in my fiancé's death.

25. My mother has no recollection of any communication or correspondence from LMTC about my older brother’s Hepatitis, if there had been any letters, I am sure she would still have them filed away in her little book where she kept details of his bleeds and hospital stays during his early years.

26. My older brother obviously told my parents over the phone about his hepatitis, whether there were phone conversations with LMTC staff I do not know. My mother like myself recalls only the marked crockery and cutlery

27. With regard to HIV testing I believe my brothers were told that that was what they were being tested for, my recollection of the time is that we waited a long time for the results. Back then the nature of the test, took a long time. I do not know exactly when the tests took place but know that by the time the results came through my younger brother had celebrated his eighteenth birthday, this is memorable because my parents were told they would not be told the results because he was now an adult. He did not see his nineteenth birthday.

28. This means the results came after the GRO-C 1986 but before December 1986 of that year when he died. I believe we knew by some time in the early summer but have no exact date.

29. I believe my brothers went to the hospital to be told but do not know if any formal letters were sent, I suspect not as if this had been the case my mother would still have the letters. Both boys were still living at home at this time.

30. I do not know what infomation if any, was given by the hospital, back then nobody knew much, other than it was a killer I am sure there were leaflets, we were none of us to “die of ignorance”.

31. I have been asked to comment on whether or not I think the infomation provided adequate or timely. What Information?

    “You’ve got it, don’t spread it, can’t treat it, it’s a death sentence.” Given with test results or soon after, timely may be correct usage, gloving up and safe sex, adequate, and has probably saved many. But given that the horse had bolted it really was only closing the stable door. So, could equally be thought too little too late.

32. There was no managing the infection back then there was no treatment.

33. That summer of '86 I recall my younger brother, Duncan developing German measles followed by coughs, colds, sore throats and thrush all signs his immune system was gone, before he developed the pneumonia that finally killed him.

34. As I said above my parents were somewhat stunned by the fact that their younger son faced his results with out them. He was to be given the information and then it was up to him whether or not he share it with them.

35. I have been asked to comment on whether information should have been provided sooner. At the time we thought they didn't have any information. This was new, it was devastating, they were doing all they could.

36. It has only been in later years that we have come to realise more could have been done, not to treat the boys once infected, the drugs now available had not then been developed, but to not have imported the blood products in the first place.

37. I now believe the powers that be knew their origin made them high risk, that clean products could have been sourced, but that choices were made that were the wrong ones.

38. I have been asked to comment on the information we were given about how to manage the infection. I really don't recall what guidance if any we were given about infection of others, glove up when treating and mopping up blood spills, nose bleeds, cuts etc. and I assume though would never have asked him that my older brother was told to refrain from or practice safe sex. He had married and seen the birth of his first child in 1984.

3. Other Infections

39. Other than HIV and Hep. I don't believe any of the above victims contracted other infections through blood products. There was a period when CJD loomed large and caused more worry. It was of course the things they caught because of their lack of immune system that were the problems. Like the German measles and the coughs and colds that could not be thrown off.

4. Consent

40. I have been asked to comment on whether I believe my family were treated or tested without their knowledge, consent, , without adequate information or for the purpose of research:

41. For my younger brother the time between being told he was infected, and his death was relatively short the treatment for the pneumonia stronger and stronger drugs. I do not recall any of us feeling things were being withheld from us.

42. The only thing we as a family were at odds with was that at the end my parents had said he was not to be put on life support. My brother was put on a ventilator the trauma of which caused him to bleed and his head and face swelled up and was as purple as Roald Dahl's Violet Beauregarde. He was in his last days unrecognisable.

43. His lungs were useless his heart weak, why had they ventilated him, it wasn't as though he could have a heart and lung transplant, they weren't providing support until his body could support itself, that wasn't going to happen. We asked them to take him off the machine.

44. The answer, I paraphrase, we can't the drugs we sedated him with will kill him, we'll have to wait three days" This postponing of the inevitable was whilst perhaps well intentioned an unnecessary cruelty.

45. For my older brother who remained well for many years without any treatment by the drugs that were being developed, he said," When I start been NR you can start treating me."
ill GRO-C

46. I feel he thought the side effects of early treatments were such that if you weren't yet ill it wasn't worth the risk. We had one or two scares, a broken leg necessitating surgery and the risks involved and an infected finger, treated with surgery/skin graft and lots of antibiotics, he got away with that one.

47. I do know that as more time went by Mr McVerry wanted to biopsy his liver to find out why he was not ill. My brother declined again saying when I'm ill you can start investigating and treating me but not until.

48. In the end it was an opportunistic cancer Burkitt's lymphoma which caused his death. He attended St. James' thinking he had pulled a muscle under his arm. He had felt "a pop" and there was a lump. He was told it was a bleed, was admitted, and for a long time was treated with Factor VIII. At 45 years of age he felt he knew his own body and whether he was bleeding and maintained he was not the Factor VIII continued.

49. He spent the last thirteen weeks of his life in hospital, but it was not until week six or seven that he went to theatre for surgery/investigations and they discovered the cancer.

50. When I later asked Mr McVerry why having presented with a lump under his arm they had not, as they would have done for anyone else, biopsied it, he said "well we didn't want to cut him he's a haemophiliac," this from a man who wanted to biopsy his liver when he was well.

51. My brother's lymphatic system was shot, he swelled up like a balloon until fluid oozed out of his skin. Two rounds of chemo did nothing and whether it was the chemicals or the cancer it fried his brain. He had lost a great deal of weight and died after suffering a cardiac arrest whilst the doctors were trying to drain his lungs.

52. I do not believe he was treated without his knowledge.

53. I do know he had to fight to stop the Factor VIII when he knew he was not bleeding, of course he was injected as necessary later in preparation for surgery.

54. I do not know as to the quality of information he was given.

55. Once discovered he was told about the cancer and the need for chemo, which began quickly. I do not know if he was told of the aggressive nature of this particular cancer.

56. I do not know whether he gave permission for any of his treatment during those final thirteen weeks to be research related.

57. I do know he was photographed, whether simply for his own medical records or for future medical reference I do not know.

58. Angry at the time that the cancer was not discovered sooner, i.e. early after his admission. On reading further, I took some comfort from the fact that even if it had been diagnosed, such is its aggressive nature, that even if there had been some remission it would have quickly returned and done its worst.

5. Impact

59. I have been asked to comment on the effects being infected had:

Duncan

60. My younger brother had little time to consider such things, he died within months of diagnosis. Towards the end I have no doubt there was an element of fear, as a family I guess we just loved him through it. There was not a lot more we could do. The physical strain of the pneumonia was devastating the pain of the coughing and the fear because you can't breathe horrendous. The last week or so he was I think sedated and totally unaware during his final few days. The effects of the, as we saw it, pointless ventilation, were on those around him, once unrecognisable, my father could not bear to visit him.

61. As a concequence of being infected Duncan got the German measles which he could not fight off. He also suffered from coughs, colds, thrush, pneumonia and death.

62. Duncan did not receive any treatment for the HIV (there wasn't any) so could not suffer any side effects from this.

Sandy.

63. For my older brother I am sure there were both mental and physical effects. I cannot speak at length about what went on inside his head. A true Yorkshire man he just got on with his life as it panned out. Divorced from his first wife, (not because of the HIV) he remarried and added two sets of twins to his eldest son. For whatever amazing reason neither GRO-C GRO-C were infected, he called his offspring his little miracles. Living on benefits because stigma meant no work, I know there were GRO-C GRO-C with much support being given by my parents.

64. I know he suffered night sweats but by and large remained well until his final thirteen weeks as detailed above.

65. Of course, the haemophilia continued, bleeds internal, injuries external, spontaneous bleeds, the resulting arthritis in his joints, difficulty getting out of

bed on a morning until he gradually got his joints moving all the usual joy of living with haemophilia. The infected finger wound was traumatic in so much as everyone knew that if the infection could not be stopped the bust knuckle caused by catching it on the bookcase could result in losing the hand, the arm, or the life. We all had nothing but praise for the surgeon who opened it up, took it apart, cleaned it, grafted new skin and saved the day.

66. Lived for many years without HIV treatment, one or two scares, broken leg, infected finger as told above, and then final 13 weeks with the cancer.
67. As far as I know my brother declined all treatment for HIV saying he would only consider them as and when he became ill.

68. There were effects from the chemo he received at the end of his life, but that is not what I think you are looking for here.

69. I have been asked to comment on if they faced any difficulties obtaining dental treatment. I know at one point there were problems getting a dentist.

70. I could never understand why given the difficulties any haemophiliac might have getting dental treatment, (Sandy had his wisdom teeth out in hospital) that once HIV raised the stakes dental treatment could not be part of their hospital care.

Steve.

71. For my fiancé as was, I cannot speak in detail, like my older brother I think he remained generally well apart of course from the ongoing haemophilia.

72. I do not know what details he withheld from me as he tried to protect me from the grief of the inevitable loss.

73. I know that he drank in the evenings so as to self-anaesthetise and be able to sleep. His mother tells me that when she raised this with a doctor his answer

was, "What do you want me to tell him, that the drink will kill him." I don't think he was drinking that much, but the doctor had a point.

74. I don't think my chap was dealing with this as well as my older brother, he had never been a good patient, and I don't think he had the same attitude towards the situation or the same support, though this was partly because of him thinking if he didn't stay attached to us, our hurt would be somehow less.

75. His final days were to say the least short. A banged elbow, and a visit to the hospital for treatment on Wednesday, ill Thursday, yellow, with I presume jaundice on Friday and dead on Saturday. I lack detail. We received a telephone call from his mother Saturday night. His plan had not worked, I was devastated.

76. Any hope of convincing him to change his mind and resume our plans was now gone.

77. I have been asked to comment on any stigma my brothers, fiance and family faced as a result of their infections:

Duncan

78. My younger brother, dead at 18, not a street wise, drinking teen about town, but still in many ways a boy, having left school, (John Jameson at Leeds) and started at our local FE college he had had Haemophilia related problems.

79. Like the time his benefit was threatened because the powers that be said he was refusing to attend or cooperate when there. This stemmed from him refusing to get into transport, a minibus, full of rowdy, physically pushy, shoving, standard teenagers. The injuries, bumps and bleeds, which could have resulted were unacceptable to him. We really had no problem with the other boys just being teenage boys but there was no recognition of his needs

or why he was not willing to get in the vehicle. He was just sanctioned for his refusal. He became ill so soon after diagnosis that his time at college ended.

80. We have a very loving extended family, and my brother had a small but very true group of friends. I do not know how much he told them, but they remained loyal. He did not have a wild and busy social life to lose, but this was the 1980s and being HIV positive was not something anyone would broadcast. The mania and stigma at this time was horrendous, tales of graves being filled with concrete and people being hounded filled the news.

81. A phrase that was in popular use was, "Good AIDS and Bad AIDS" i.e. poor souls like my brothers who did not deserve it, whilst others whose life style choices somehow meant they did, could suffer and die without anyone caring. The reality was society at large may take the heading from the tabloids but really didn't give a damn which group you were in, you had it and therefore must be shunned, consequently you said nothing. Let's face it, good or bad you were just as infectious and dangerous to know and were of course going to be just as dead.

82. Who knows what is in the head of an eighteen-year-old who has to listen to this, and know "that's me"?

83. His life outwardly changed little until his final admittance to hospital, the physical pain of the pneumonia the fear and mental torment of knowing you are going to die, I don't know what that does to anyone.

84. The word I want is not "fortunately" but my younger brother did not live long enough for the blot to blight his life in any other way than ending it.

85. He died in a world that hated people who were infected, protected from it when possible, by those who loved him.

86. (I need to say at this point that no-one in our family ever considered the fact that some people deserved what they got, however they were infected with this odious virus. Our own disgust, amongst ourselves, directed at those who

thought it meet to condemn or harass "lifestyle" victims. This inquiry concerned as it is with those affected by blood products might just at some point take a moment to consider those who with good or bad AIDS were brave enough to test products that now sustain so many).

Sandy

87. My older brother lived much longer with his lot.

88. Only now when asked to say how his life was impacted by HIV does it strike me that I know so little. He lived the life he had, we none of us know what might have been. As a family our lives have generally been simple, you work for what you have, you enjoy what you've got, you don't care about the Joneses, and there is always lots of love.

89. I cannot say what effect infection had on his relationships.

90. His first marriage ended, but not because of the HIV, however the infection was massively present in the resulting custody settlement. My brother's first wife was, without passing any judgement, from what would now be called a GRO-C He loved her very much and I think Pygmalion like, hoped that in offering and providing "better" could give her a different view of what life could be like. However, in the years they were together GRO-C Again, without judgement I tell you,

GRO-C

91. My brother, his wife and son lived in our family home and when the marriage finally ended it was my brother who left. He had found someone else. I can't say we were happy about this but with or without the third party the marriage was over.

92. I tell you this, so you can appreciate how it links to the matter in hand. My brother left and filled for divorce however he did not feel, due to his HIV status that any court in the land would give him custody of his son.

93. Before his first visit to the solicitor he came to the family home and asked my parents if they would take legal custody of his boy, this would mean the child would remain in the same home as he had always lived in, with the same family around him and remain at the same school he had recently started. My parents agreed and to her credit so did my sister-in-law, saying "yes he'll be better off with Grandma and Grandad."

94. Had his wife asked for custody GRO-C my brother made it quite clear he had considered the possibility of GRO-C GRO-C

95. My nephew grew up with us enjoying a good relationship with his dad, seeing him many times most weeks. His mother eventually left our home after beginning a new relationship, we have seen her only occasionally across the years GRO-C

96. I tell you all this not because it is unique, marital breakdown is seemingly more common than its success, but because my brother had had to consider the fact that if he applied for custody his wife could contest it on the grounds of his health GRO-C

97. My brother lived until his eldest son was eighteen, he did not know he would do this at the time of the divorce when the child was five but in terms of impact and life changing decisions, I think this is a big one.

98. My brother married the third party, they had two sets of twins, they were for the most part happy, no relationship is without its hiccups, as I said above, we are generally a quite unassuming and quiet family.

99. My brother lost his job, company take over, HIV, who knows the whys and wherefores, after trying self-employment, he didn't work again. Life on benefits is not easy and financial worries were often uppermost.

100. My parents and I supported him and his family GRO-C on many occasions GRO-C. I say this not because we expected to or because we begrudged it, but just because it must be true of so many of the families giving evidence to this Inquiry.

101. Like my younger brother my older brother was supported by family, none of our relations shunned him, his family or us because of what we were going through, of course on mums' side of the family where the haemophilia hailed from relatives were in the same boat, but dad's side of the family never wavered either. Like our younger brother he had a small but loyal group of friends, they knew, and they stuck around anyway.

102. We have heard tales of people being harassed and discriminated against, maybe because our world was small and close knit, we were protected from it. We knew it was happening to others, but we just got on with our lives as they were being dealt us.

103. Troubles like not being able to fly off on holiday because of the medication you needed to take never came into our lives, we camped on a farm in the Yorkshire Dales it wasn't an issue. So happy there with friends that it's where his ashes were scattered.

104. The more I write the more I worry I begin to waffle, the more I think I'm saying everything was fine, perhaps a simple ordinary life is more difficult to spoil or disrupt. I would like to point out however it was no more difficult to destroy. My older brother may have lived longer with the infection, because he chose to accept no experimental or proven treatment, he may not have suffered the side effects or subsequent additional treatments others underwent or were denied. I would however like to point out that he is just as dead.

105. I close this section with a question: During his final illness and in great pain my brother left hospital for the afternoon of the birthday of the eldest twins, GRO-C GRO-C they were thirteen GRO-C NR. By the GRO-C the birthday of the younger twins, they were twelve GRO-C NR. He was dead. What do you say to a child when they say…"Daddy came home for their birthday, he promised he'd come home for ours, he lied"?

Steve

106. My man was not a good patient, never resigned to his haemophilia, never comfortable with his treatment, couldn't self-inject. As his mother said, and I paraphrase, the haemophilia we knew about, we learnt to live with it and treatment had improved so much since the days of her father and my grandfather. But this was something else, we didn't know what it was, we had no control over it, it has stolen the lives of men we had grown to expect would see old age.

107. As far as I know my fiancé and his family learnt of his diagnosis whilst he was living on the GRO-C and registered at Inverness, whether he was infected by treatment from there I do not know he had previously lived in Oxfordshire and like my older brother had attended LMTC in the 1970s.

108. He lived with his father and after diagnosis though not immediately they moved south to Somerset to be nearer his sister.

109. I do not know details of how he faired I think his physical health like my older brother was reasonable, though I suspect his mental health was more troubled. As I said above, he drank to sleep, though I do not know if this ever became problematic.

110. Although we remained in contact after he withdrew his marriage proposal, I know he withheld things from me. He seemed to think he could protect me

from the hurt by distancing himself. Not true. I made a conscious decision not to contact his mum about this before writing this evidence as the evidence I give should be mine.

111. I don't know for certain but think she was involved in the Scottish Inquiry and may be submitting her own evidence to you. I made contact with her in 2017 for the first time in many years and hope to see her soon.

112. I cannot say in detail how my fiancé was affected physically or mentally, what is it that makes a man withdraw an offer of a life times love because he knows that lifetime is to be cut short. Perhaps he thought it a greater act of love to release me.

Impact on myself

113. When the news of the Inquiry was announced, and my mother and I attended a Haemophiliac Society Meeting in Manchester we met many people with many reasons for being there. I later attended a meeting held by the Inquiry team, also in Manchester and again different reasons for being there were expressed.

114. We were asked what we wanted from the Inquiry, for some it was an admission of responsibility, for others financial support for them and their families as they continue to struggle, some want guarantees that future products will be safe for the next generation, (we have young haemophiliacs in the wider family) the reasons are as numerous as the victims.

115. For me, I wanted openness, I wanted the stigma which exists to this day to be defused, and I want a recognition of the ripple effect of this disaster. Because of this disaster I am single, because of this disaster I have suffered mental health issues, because of this disaster my career has been affected, because of this disaster my financial future is not what it should be.

116. I am a sister, not a parent, not a wife, no compensation, just year on year of getting on with life, supporting those around me, hoping we'll get through it and telling the outside world we're fine.

117. For over thirty years my life has been affected, without any recognition, other than from my immediate family, of the grief and the worry and the weight on your shoulders that you carry around because of this disaster.

118. 'til now my evidence has I feel been a little vague, my younger brother died soon after diagnosis, difficult to say how it affected him over that short period, it is over thirty years ago, difficult to remember. In chronological order, my fiancé was next to die.

119. As I said above this happened very quickly, Wednesday to Saturday, not September to December like my younger brother, at least with him we had had some little time to prepare.

120. After losing my fiancé (and yes, I do still call him that, because I believe that had it not been for this disaster, he would not have withdrawn his proposal.) that idea of knowing what was coming and when vanished, from then on we had to live with the knowledge that my older brother could die at any time without notice. At the time of my chap's death, my older brother was married with three children and his wife expecting a second set of twins, that death could come at such short notice was yet another slap in the face.

121. And so, I begin to tell you how this has affected me. It has been over thirty years, that is more than half my life time.

122. Physically, I cannot say I've been affected, a little too much comfort eating perhaps, but not infected by a partner or ground down by physical graft of caring for a loved one as will be the case for many of your witnesses.

123. Mentally, I was already an adult when this hit us. In the summer of 86 I left my job in banking to return, as a mature student to college. I was training to be a

Nursery Nurse. It was in December, at the end of my first term that my younger brother died. I don't remember it affecting my studies, like so many other events through the years we were just matter of fact about it and got on. I had told my senior tutor, but in the highly charged atmosphere of the time it went no further. My lasting memories of this time are: -

124. We were not allowed to remove his body from the hospital, the undertaker had to collect him from there early on the day of the cremation and take him straight to the crematorium, where we met them. He was the first cremation of the day.

125. His funeral was on the last college day of term and after we returned home, I went in to college, just to show my face and say "Happy Christmas" to everyone. I remember feeling that if I didn't then come January I would struggle to go back and face everyone. I didn't change out of my grey suit and when I walked in, I remember one of the tutors saying, "Oh you look very smart, have you been somewhere nice?" Without thinking I answered, "No I've been to my brother's funeral."

126. That poor woman, she wasn't in the know, she didn't even know he'd been ill, because in 1986 "It" wasn't talked about.

127. This was the first time I felt guilty, because "our problem" impinged on others. She was so apologetic for something that was not her fault. It was then or certainly soon after that I decided I was going to be completely open about what was going on. Not broadcasting, but not hiding. If anyone asked, or if anyone needed to know I would willingly speak. It didn't make the guilt of "our problem" impinging on others go away. Even now when I'm talking to people about the inquiry and writing this evidence I worry, you can see the horror in their faces at what we've been through, and the sadness that comes over them.

128. After my NNEB training I continued my studies signing up to do my B.Ed. Hons. Initially at Newcastle Polytechnic. (yes, we still had those back then)

However, after two weeks I returned home finding I could not be away from my nephew. I worked as a Nursery Nurse for twelve month and then started my degree at GRO-C, meaning I could live at home.

129. There were deaths of haemophiliacs, both friends and in the more extended family but it was whilst I was doing my second-year teaching practice that I lost my fiancé. He had as I have said above withdrawn his proposal and speaking later to his mother, we concluded he did this after receiving his diagnosis. He said he wanted to spare me going through the loss. It didn't work.

130. He died on the Saturday, I went into school on the Monday, did a days teaching and told them I would need Tuesday, Wednesday and Thursday off to travel to Somerset for the funeral. I returned went to school and taught on the Friday, finished my teaching practice broke up for Easter and after the holiday returned to college and continued with my course. I just kept on going.

131. I completed my third year, including my teaching practice, though my marks were declining, I was finding it difficult to do assignments both in terms of the academic rigor and the physical act of just writing them (back then by hand). I remember thinking that if I did my third-year teaching practice someone else would die.

132. Into the fourth year. Prior to breaking for the summer holidays, I prepared for my final teaching practice. It would be the whole of the Autumn term of my final year. File all signed off and ready to go.

133. First day of term, I can't do it. I got up, got ready but could not leave the house. It may have been some time coming but I'd finally broken down. I had to contact the school and college. Visits to the doctors resulted it my taking out the whole term.

134. My grant had to be returned and arrangements eventually made for me to return after Christmas, do the rest of my final year including my final exams

and postpone my final teaching practice a full year returning for a fifth year in Autumn 93. I was then given until Feb 94 to complete any related assignments. Having been notified that I had passed, I worked as a supply teacher and nursery nurse, then graduated in Dec 94 one year after the rest of my cohort.

135. From a time when I thought I would not complete my studies, or if I did, only scrape a third, my two-two was very welcome. It had not been easy, and the struggle had lasting effects, many times I have asked myself was it the bereavements or was I just rubbish. It is so easy to believe the latter even after twenty-three years in the classroom as a qualified teacher.

136. I have worked in two amazing schools with very supportive staff and count myself more than lucky to have had the career I have had. However there have been times when things got too much. We hear so much these days about teachers under pressure and I'd be the first to admit it's not a profession for the work shy or faint hearted.

137. For me my mental health issues were intermittent. By and large the loss of more extended family members and hearing about friends from my brothers' schools almost became second nature. You learn to laugh it off, "I've got a season ticket for the crem.," "I get withdrawal symptoms if I don't visit it at least three times a year." Hugging family with comments like "Fancy meeting you here" or "Here we are again."

138. All families have loss but the relentless nature of our experience just grinds you down.

139. I've had counselling, once through my GP and once through work.

140. When I broke down at the beginning of the forth year of my degree I told my GP I'd stopped answering the phone because every time I picked it up someone had died, he gave me an A4 questionnaire the last question on it wanted to know had I had thoughts of self-harm or suicide, the answer to this

was yes, for about a nano second, but it wasn't an option. Why? Because my mother deserves to have one of her children out live her.

141. How's that for the first item on you bucket list? Out live your mother. A counsellor I spoke to at the time said that what I needed were "strategies for coping with stress" I told her "I just need it all to go away." IT NEVER DOES.

142. Much later, through employee health, I met a lovely lady. A counsellor who said, "You really are a glass half empty person." "No" said I "someone's smashed my bloody glass." (there was no pun intended).

143. After the employee health sessions, (these were good, because they allowed me to pour my heart out with out adding to some one else's burden. Mum and other family members have their own version to deal with, so someone who's paid to listen without being personally involved, really was good.)

144. My headteacher asked," How are the sessions going? you seem to be coming along." Various phrases, a little conversation, all well intentioned, things are looking up, he thinks. And then you realise, they just don't get it.

145. Yes, it helps a little, temporarily, let off steam, get it out of your system, have a rant, have a cry, dry your eyes, your hour is up. Walk out into the rest of the day and guess what, THEY ARE ALL STILL DEAD.

146. My career has been affected. I have fluctuated between full and part-time work to relieve the pressure, and for some time worked as a classroom assistant, this meant I was still working with children enjoying a post in class but didn't need to be working into the small hours marking and prepping.

147. The time after school was mine, I could if I wanted do things for school, or I could spend time with family, or if I needed to, be by myself. I am quite sure that had my mental health not been affected by events I could have coped with the not insignificant stresses and strains of primary school teaching in the 21st century.

148. I also considered doing my Masters but had come to feel I would not be able to cope with the rigor needed to gain a higher degree.

149. There have been financial implications, reduced salary when part-time, muchly reduced salary when working as a classroom assistant and to the future, a pension that is not as it should have been, and that just gives you more to worry about.

150. Emotionally: the sadness, the anger, the guilt, they are HUGE.

151. The sadness like the depression comes in waves, triggers are varied and many. The classic, a certain piece of music, visiting a significant place, a meal, to be honest anything and everything, those you know you avoid, but silly little ones catch you unaware.

152. Family occasions: I didn't enjoy a wedding for years. You're there your happy, you love the newly-weds, then there they are, all the thoughts of what might have been. The scream you hold in when someone at the nuptials smiles and says "your turn next."

153. Would my brother's children have turned out differently if he'd been around? That one's a biggy at the moment now the youngest has died in an industrial accident (Sept 2018) and it features in anger and guilt as well. Anger with them for not trying harder at school and anger with myself for not making them. But then I don't suppose school seems that important when you've lost your dad. You certainly don't need a nagging aunt. And there's the guilt, it doesn't matter what you do, you can come up with a reason for feeling guilty.

154. Not doing enough for others, doing too much, saying the wrong thing, none of which are exclusive to people bereaved by HIV. But I find that whenever emotions rise good or bad it is never very long before a HIV / bereavement thought /feeling follows.

155. You want to enjoy it with the lost person, it reminds you of them or something they did, the guilt lies in the fact you are not giving the people here and now your full attention. You are not living in the past, it is not deliberate, but it never goes away.

156. Some guilty feelings come and go, but some are so huge. My dad had dementia before he died, he used to ask where my brother was, "we've not seen him for a while" My mother and I would lie. "oh he's probably busy with the kids or the car, he'll come when he's got time."

157. When I was visiting employee health, I said that statistics showed that had I married my man we'd probably be divorced by now, guilt trip. Thought, people who marry for a second time are using up my turn. People who still have their siblings and moan about them should try losing them.

158. Sadness, anger, guilt, the terrible trio they are not always there, but they are never far away.

159. As I have said above, we have always been a quiet, close-knit family, our circle of friends likewise. I cannot think of anyone who mattered to us ever causing us any grief with their attitude or comments about what was happening. They have not been over bearing with their "support" or "love" but let our lives continue as "normal" as possible, there when needed.

160. The atmosphere in the country in the early days of mania and panic made us all wary of broadcasting our situation. It was not something you told anyone who didn't need to know or didn't ask. It was the constant bombardment of newspaper reports, TV news and programmes speculating about what was going on, telling us what a disaster we were living (or in most cases dying) through. Tales of people being buried in lead coffins and graves being filled with concrete to stop "IT" escaping. Was this going to happen to us.

161. In truth I think the worry and mental torment was as with so many things worse than the reality. When the time came for my younger brother's funeral,

we were not allowed to bring him from the hospital. He was taken by the undertaker from the morgue straight to the crematorium. For a long time I did not know what happened to his ashes, through the process of preparing my statement I have inquired and found out NR ashes were scattered at the cermatorium.
his GRO-C

162. When my fiancé died his mother wished him to be buried, she was told this was not possible, and that he would be cremated, she stood her ground, asking if it was because of the HIV and was told "no, the Hep.C was the problem."

163. She got her way, things were changing, his funeral, a burial, was, on the day seemingly as any other. My older brother was taken to the undertakers, people were allowed to visit and to view, his cremation was in the afternoon, my heavens we are nearly normal.

164. We have been through all this and more and just got on with it. Now in terms of stigma and societal pressure things seem from where I stand to be less pressurised. I from quite early on was willing to tell people, I never hid what they had died from, my mum and others did and still find it easier to list secondary causes, the cancer, the pneumonia etc. perhaps adding "of course their immune system couldn't fight it". If the listener puts two and two together fine, if not that's fine too.

165. Speaking to people now it still sometimes catches me unawares when people say, "Oh that's awful, I had no idea". It makes you realise that whilst we were all living with the constant bombardment of the panic and mania, the news items and press reports that so often felt they were aimed directly at and were about us, that, being aware that grinds you down, the vast majority of people just listened and let it go. I guess most of us only really pay attention to those things that affect us directly.

166. People sometimes seem surprised that this is still ongoing, that the ripples of this disaster are still affecting people, and that one of the things we want is

that the stigma needs to go, so that we can speak without dread of repercussions. Compared to dealing with the illness and the deaths, the stigma and what others think may seem a lesser part, and it is, but it is as I have said before the cumulative effect of all aspects of this disaster that grinds you down.

167. I have no doubt what so ever that losing their dad affected the education of his four twins, eleven and twelve at the time of his death, though in terms of end results I cannot say whether any of them would have fared any better had he still been around.

168. One of his boys was excluded from school and sent to GRO-C GRO-C the local FE college, his twin left school in solidarity. As we had little GRO-C we only found out about this later. I don't know the whole story or why this was allowed to happen.

169. My sister-in-law cut herself and the children off from us after my brother's death, GRO-C GRO-C When the younger twins renewed contact as young adults a passing comment on how well one cooked was answered with, "Well when dad died mum went to pieces GRO-C"

170. As I have said, when you've lost your dad school may not seem important.

171. In the summer after my younger brother's death, our cousin, two years his junior and best friend GRO-C

GRO-C

172. My younger brother's time at college was cut short by his illness and death, he was not an academic, and I do not know what line of employment he would have gone in to had he lived beyond eighteen.

173. My fiancé had various jobs after Treloar but on GRO-C ran the B&B with his dad, family/self-employed, no-one to sack you if you're working for yourself.

174. My older brother was very fortunate after a short period of unemployment after he left school, he gained a job at a local engineering firm where a friend saw the opportunity that would be mutually beneficial. The company had a part time post, working on the shop floor and driving. They had employed many but because of the part time nature they had often moved on quickly to jobs elsewhere with more hours. The deal was this, the job was part-time when my brother was well, he would work as much as he could, a full 40 hours a week if fit enough. This might prove to be several weeks running, if however, he had a bleed and needed time off that was fine he had accumulated plenty of hours or would make them up working full time on his return. A small family company, a wonderful arrangement, he worked very hard was muchly appreciated.

175. When the HIV came along those who needed to know knew and bosses and colleagues were fine and supportive. Come the takeover, such mutually beneficial / wishy washy arrangements could not be tolerated. Whilst not the only one laid off I don't think the new bosses needed any excuse to make my brother one of the first out of the door.

176. After this my brother tried self-employment, it didn't last, and he spent his remaining years living on state benefits.

177. I've written above about the effect on my studies and my career, I do believe that my mental health issues affected my ability to study, and that this affected my confidence and self-belief. As the years have gone by, I know I have not done things because "What's the point? I'll just get started and something will come along and mess it up."

178. People with a "go get it" attitude say "be positive" or "well if you're going to be like that, you'll never achieve anything" as though how we feel is a choice, it isn't.

179. I wouldn't wish my worst enemy into the dark places I've been. In the last couple of years mental health issues have risen in the public eye and thank heaven for that, but for the vast majority of the thirty plus years I've been living with this disaster it has been in an atmosphere of, "Oh, get over it, get out there and find somebody else, its over and done with, move on, stop living in the past, GET A LIFE!.

180. Our lives as they should have been, have been stolen from us, as surely as the lives of those we've lost.

181. In terms of other family members, my father's dementia, not caused by the disaster, but daily made worse by the fact he had no understanding that his son's were dead and therefore questioned their absence, especially that of the eldest whose death came during his living with dementia. The "little white lies" we'd tell of how he was busy and he'd call when he could.

182. And my mum, down two sons and a prospective son-in-law, cousins and friends. A rock, supporting the rest of us whilst quietly getting on with life.

6. Treatment/Care/Support

183. I have been asked to comment on support myself and family may have received.

184. I do not believe my brothers encountered any difficulties or obstacles in the treatment, care or support they received. Financially Sandy probably encountered red tape getting his mortgage. In terms of care and support beyond the medical, it was not perhaps what we would expect today. For example, no counselling, no complementary therapies, no memory or keepsake making for the twins. None asked for, none offered.

185. I do know that my fiancé had little regard for the hospital in Inverness and after moving to Somerset seemed happier with his care. They had a buddy system, but I don't know whether this was through the hospital or a charity.

186. I have had counselling through my GP and our local authority employee health scheme.

187. This was not offered because of the HIV disaster as something that should be offered to all those of us affected. But was given as to any other member of the population when I presented at the doctors in need of a sick note because I couldn't cope. The employee health support was offered when my headteacher decided all was not well.

7. Financial Assistance

188. As far as I know, my older brother had a payment from the MacFarlane Trust as did my fiancé, my parents received my younger brother's payment posthumously.

189. I understand my sister in law received a postumous payment from the Skipton fund when those payments were made, though my parents received nothing for my younger brother from this fund as he did not contract HCV.

190. My brother was given help getting a mortgage, but once he died and GRO-C GRO-C

191. I do not know if my older brother received any further payments from the MacFarlane Trust.

192. I think we found out about the Trust payments by letter, I know my parents had to go to the hospital to sign for it. They did not want it, but as the nurse said "take it Mrs Martin, its not much but if you don't they'll just put it in the arms budget."

193. My parents had only the one posthumous payment for Duncan. I do not know if Sandy had any difficulties or obstacles in applying for any further financial assistance?

194. As far as I know my parents had to sign like everyone else to say they would take the matter no further before they were given the "compensation" for my younger brother.

195. I do not know what if any conditions were imposed on my older brother with regard to the mortgage or what other payments he received conditions or not. Once with his second wife the dealings were theirs not ours. I do know my parents GRO-C.

196. In terms of the scheme I would say: What price a life? The money my parents received was a pittance, and the money my older brother received soon gone, GRO-C GRO-C

197. A pittance, at the time we never used this word, the money was not the issue, and the money my parents received for my younger brother sat in the bank untouched for years. It was later when my older brother heard of payments made in other countries that the word was used by others and came into his and our vocabulary.

198. Incidentally, when my older brother died and not knowing my sister-in-law's immediate needs my mum went to the bank to draw out some money in case it was needed. It was to come from the account they had opened to deposit my younger brother's compensation in, it had been sat there since the cheque had been paid in.

199. GRO-C

200. Never has the phrase "Dirty blood money" come to mind so readily, caused so much hilarity and pain.

201. I have not received any financial assistance from any of the Trusts or Funds set up to distribute payments. I was not next of kin to any of those I lost, therefore not entitled to anything but the pain.

8 Other Issues.

202. Under this section I state, I have had no involvement with any earlier litigation inquiries or campaigns related to this matter of contaminated blood products. I have not requested my brothers' medical records, and have not yet decided whether or not to do so.

Statement of Truth

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

Signed **GRO-C: Helen Lesley Martin**

Date: 13/9/19