Witness Name: GRO-B
Statement No.: WITN0477001
Exhibits: WITN0477002
Dated: 28th November 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11th April 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B 1952 and my home address is known to the Inquiry. I am married to my husband GRO-B and together we had two children, the youngest is our daughter, GRO-B. The eldest, our son GRO-B: S tragically died in GRO-B 2018 aged 39. It is for S and his family, that I provide this statement. We have a granddaughter, S daughter GRO-B with his wife, now widow GRO-B GRO-B. I intend to speak about how my son, S, came to be infected with the Hepatitis C virus (HCV). In particular, the nature of his illness, how the illness and the knock on effects had affected him, the treatment he received and the impact it had on him and our family.

2. I should point out from the start, that this statement has been written from the combined memories and accounts of myself and GRO-B and where it relates to only GRO-B memories I will identify that. This process is very challenging for us with S passing still so raw and it is only now that we feel able to approach it as we feel we must. However, it would have been too painful for us to have both been interviewed and to provide two full statements to the Inquiry, fundamentally saying the same things. In terms of S story, it would be the same account. I will also provide some elements of impact on behalf of GRO-B who, at 11 years old is too young to do this for herself. GRO-B has not yet been able to provide a statement due to her own state of mind, dealing with S passing. She is however represented by a legal firm. I do not know when GRO-B will feel able to provide a statement, if indeed she ever will.

3. There will be things that I mention that are not directly relevant to the contaminated blood products S was given by the health service and more to do with his haemophilia that nobody could have prevented. However, GRO-B and I believe that it is important that these things are included for context, because of the compounding effect the infected factor VIII had on an already very difficult condition that S had to contend with and by extension us, GRO-B and GRO-B also. I would like to say that none of what I say on behalf of us both, is intended to gain pity or sympathy for GRO-B and I. We went through a hard time, it is what you do as loving parents. However, we think of this as nothing compared to what S suffered or what his wife and young daughter went through when he was alive and will continue to grieve over, for a very long time after his passing.

Section 2. How Affected

4. GRO-B and I were married in GRO-B 1972. After 7 years together, we decided to start a family. We wanted to be in the best possible position so that everything was just right. At that stage of my career, I was in

finance, working for the Nationwide Building Society. Fortunately, back then, staff who had been working there for a certain period of time were able to obtain a staff mortgage at an extremely preferential rate and so we were able to buy a house in GRO-B. Around the same time, I began to make personal health preparations such as changing my diet so that my body was in the best possible condition to carry a baby. It was all planned out and in 1979 our son S was born after a very quick and uncomplicated labour. Everything seemed to be as perfect as we had planned.

5. The 'bliss' of family life was soon disturbed when at about six months old, S was diagnosed with the severest Haemophilia, 'A'. When this was established I reflected that immediately after his birth, S navel, where the umbilical cord had been cut, had taken a long time to heal. This had not been picked up at the time and connected to the possibility of S having haemophilia but by 3 months old S was getting awful bruising on his body. We took him multiple times to the baby clinic, where initially our parenting was questioned and there were inferences that somehow GRO-B and/or I had been responsible. Eventually, we took him to the GRO-B Hospital where they performed a number of tests on him, one being to test for cancer, but they all came back clear. So, it wasn't until he was about 6 months old when S was finally diagnosed as having severe haemophilia A.

6. When S was 6 months old, Dr GRO-B became our GP. He was a fantastic man and he changed our lives for the better. He had worked at a Haemophilia Centre at a hospital in Manchester so he knew a lot about haemophilia. This proved to be such a godsend, as outside of haemophilia centres, it seems that very little was known about the condition. Dr GRO-B was able to explain about the haemophilia, but we were in such a state of shock, it was difficult to take it all in and understand it at the time.

7. Haemophilia wasn't explained to us very well at the hospital after S diagnosis and neither GRO-B or I really knew what it was, so we decided to do some research of our own, bearing in mind we didn't have internet back then. We learnt that it was passed down the family line through females acting as 'carriers' of the condition. We had no knowledge of haemophilia in my family, because there had been no male members for three generations; my mother was illegitimate, as used to be the term for children born out of wedlock.

8. We figured it must have been passed down through my maternal grandfather S Great Grandfather), who no one in the family knew. We were absolutely destroyed by this discovery. As a consequence, our lives and future took a completely different direction to that, that we had previously imagined.

9. Due to S haemophilia, I was unable to work for many years as he required care 24 hours a day as an infant. He also needed to be treated for his 'bleeds' at the Haemophilia Department at Nottingham Hospital, which was our closest Haemophilia Centre, 60 miles away. We would make this trip day or night, sometimes twice a week, as required. We tried not to wrap S in cotton wool as everyone else around him seemed to want to do. We wanted him to have as normal a childhood as possible.

10. At the Haemophilia Department at Nottingham Hospital, S was originally treated with cryoprecipitate and then at some point, they moved him on to Factor VIII.

11. Dr GRO-B went above and beyond his duty in his treatment of S and the assistance that he provided to us. One day he asked me whether we had been offered home treatment or home therapy, which we hadn't. Dr GRO-B knew that at the time I didn't want to be trained in giving S his injections, as it was very difficult to find his veins when he was little, so because he lived only a few minutes away from us, he offered to come to our house himself and he would administer S his Factor

VIII. The first injection he gave to S was on the 15th September 1981. I must say that Dr GRO-B was amazing. He stuck by us over many years and he would always be there if we had any issues.

12. I have kept a record of the home therapy (including factor VIII batch numbers) that S received, beginning in September 1981, when Dr GRO-B first started administering S Factor VIII. Dr GRO-B administered Factor VIII to S from September 1981 until December 1985 when I took over. The only exception was when Dr GRO-B was away or when we attended GRO-B Hospital instead.

13. By this stage, S was under the care of GRO-B Hospital as they had just recently opened up their own Haemophilia Department. This made our lives considerably easier as it halved the distance we had to travel in order to get S treated. It was at GRO-B Hospital where Sister GRO-B trained me to do S injections, which as previously stated, I took over doing from Dr GRO-B from December 1985. Again, all logged in the record that I kept up to and after S took over and began self administering his own Factor VIII in 1990. Even after that time, I was still administering Factor VIII to help S In less than a year, S was predominantly responsible for his own administration.

14. In terms of procuring the Factor VIII; from 1981 GRO-B had an arrangement with Nottingham Hospital, whereby he would ring up during the week to ask them to organise further supplies of Factor VIII. He would then drive to collect it on a Saturday morning when he wasn't working. He did that whenever we were getting low and once the Haemophilia Department had opened at GRO-B Hospital, he had the same arrangement with them.

15. In 1982, with S now being treated mostly at home, our lives became a lot less restrictive. We began to think about having another baby and we spoke to Dr GRO-B who advised us that we should be trying for a girl. He mentioned that a test to determine whether your unborn baby

has haemophilia had become available. This test was called a fetoscopy and at the time it was only done at Kings College Hospital in London. Once you were pregnant, they performed a procedure on you that is similar to an amniocentesis where they collect fluid from the umbilical cord, with which they do the test.

16. Dr GRO-B also suggested we did a number of other things to offer the best chance that we would conceive a girl, such as checking my temperature on a daily basis and ensuring correct timing. We felt a bit like battery hens, however we did everything we were told to do and we had the new test in London only to be given the bad news that their recommendation would be to have a termination as the baby boy inside me had severe haemophilia. We did as was recommended. This was a really hard time for us.

17. In 1983 we tried again for another baby and that was when we had GRO-B and we knew our family was complete. Unfortunately, GRO-B is a carrier of haemophilia as well. She currently lives in GRO-B and works in London.

18. When S was about to start school, we faced many issues due to his haemophilia. Our local school wasn't happy about S attending as they were worried he was too big of a risk and they initially insisted S went to a special school, predominantly for severely disabled children. We were disgusted at this and refused, as we wanted him to have as normal a childhood and education as could be achieved.

19. After many discussions about the issue of which school S would be going to, the local school which was our preference, came up with a solution that S would have an ancillary teacher with him while at school. This role would be called Teaching Assistant now.

20. Before S started at school he was the most bubbly and outgoing little boy. Once he went to school he became very unhappy. We had to take him to school every day and meet his ancillary who would hold S

hand at all times and he wasn't able to do anything or go anywhere on his own. He became singled out as being 'different' and couldn't join in with games in the playground, always having to remain on the periphery. They were so worried that S would get knocked and have a bleed. He absolutely hated it there. On weekends he would be so happy, playing football and bike riding with his friends, then on Monday he would be shackled and wrapped up in cotton wool all week. No matter how tough school was for S though, he never once refused to go as he never wanted to be different, he only ever wanted to be regarded as one of the class and accepted.

21. After a few years a new Chief Medical Officer came to GRO-B schools and agreed that S didn't need such close supervision. She planned for another ancillary who was looking after a young boy with Muscular Dystrophy to look after both him and S. It was much less restrictive and made S much happier.

22. What I want to speak about now is something that happened at GRO-B GRO-B Hospital, which changed S outlook and our lives forever. In the Autumn of 1986, when S was 7 years old, I took him to be reviewed at GRO-B Hospital, which is something that we did regularly. On this particular occasion S was in a room having his blood taken, while I waited in another room nearby. During the appointment, S overheard his name being spoken alongside the mention of HIV by a medical member of staff. We knew nothing of this at the time. S kept this to himself for many years and it wasn't until he was a teenager that he told us about it. He had thought he was dying and he hadn't wanted to worry us. It is heart breaking to think that S kept this to himself for all that time. If we had known then, we may have been able to do something about it and eased S anxiety. This we believe was the catalyst for S mental decline.

23. S kept this all to himself and we now know that he ruminated over this, with it slowly eating away at him. It was around the time that there were

these alarming public health information films, shown between programmes on television about AIDS/HIV and I remember he used to watch the news and hear about HIV and AIDS and who might be at risk; homosexuals, haemophiliacs, drug users, seemed to be always at the forefront. Looking back at this time, we had gradually begun to pick up that S was always watching the news and something wasn't quite right but we could never put a finger on what it was. We noticed a deterioration in his whole demeanour from this time. I should say, however that to our knowledge, in connection with Haemophilia and AIDS, S was never the victim of 'stigma' by others, as we know happened to other haemophiliacs during this period of fear and ignorance.

24. A few months ago, I helped S wife GRO-B apply for all S medical records from the hospitals that S had been involved with; GRO-B in GRO-B, GRO-B, Queen's Medical Centre in Nottingham, Royal Hallamshire in Sheffield, Queen Elizabeth II in Birmingham, Guy's and St Thomas' in London, Manchester Royal Infirmary, GRO-B and also his GP records. I know that GRO-B has received some but not all of these records so far. I know that Nottingham University Hospitals have written back to GRO-B to say that they no longer hold the requested records, having destroyed them in line with NHS policy. These records would have related to S treatment when he was a little boy. I have to say that in spite of using Sir Brian Langstaff's authority, which we downloaded and attached to all GRO-B applications to these hospitals, the process was frequently hamstrung by the hospitals citing issues such as power of attorney, probate and requesting letters of administration.

25. With regard to S home therapy, we always tried to act as a team. I may have been the one who administered the Factor VIII but when GRO-B was at home (ie not at work), he would get everything ready beforehand. In this way S could see that we were all in it together as a family, far as that could be achieved.

26. When S was around seven or eight-years old, GRO-B remembers one time when he was preparing the kit for me to give S an injection of Factor VIII and S asked him whether it would kill him. GRO-B reassured him that he would be okay. At that time, we knew nothing of the overheard conversation in GRO-B Hospital but it seems likely now that S had made a connection between Factor VIII and HIV with the attendant implications.

27. Around that time in mid '80s, there were sometimes stories on the news about people with haemophilia becoming infected with HIV. I believe this is how GRO-B and I found out about infected blood too.

28. S may have also overheard a conversation that GRO-B had on the phone one day. On this particular day, GRO-B had been arguing on the phone with Dr GRO-B from GRO-B Hospital, as he had wanted to give us American Factor VIII for S We had heard on the news and read it in the Haemophilia Society Bulletin, that there were problems with Factor VIII coming from America, so GRO-B refused to accept it. Dr GRO-B was putting up a very strong case that we should use American Factor VIII and he had said GRO-B had been reading too much into what he had heard about it. GRO-B then rang the London Haemophilia Society to learn more about the safety of American Factor VIII and to ask why he couldn't be given British Factor VIII. He hadn't known at the time that British Factor VIII was also contaminated. Once again, GRO-B was told that he was being overly cautious and that he was worrying too much.

29. He finally got a phone call from David Watters, General Secretary of the Haemophilia Society. Mr Watters complained that GRO-B had rung the London office over four times that day and asked what the problem was. After GRO-B had explained his worries to Mr Watters, Mr Watters responded with words to the effect of "I don't know why you are worrying. If I was a haemophiliac, which I'm not, I would have no issues with using American Factor VIII".

30. After that conversation, GRO-B rang GRO-B Hospital back and something must have happened between the GRO-B Hospital Haemophilia department and the London Haemophilia Society, as we were told that Dr GRO-B had fortunately found some BPL product in the fridge that he could give us. I believe S was aware that this event had happened, however whether or not it added to his already worried state, we will never know.

31. As I stated previously, when S was about seven years old we began to see a change in his demeanour. He wasn't the bubbly child we knew; there was no sparkle in him anymore. I believe that part of the reason for this was the negative impact of his maternal grandfather. My father was one of 13 children and an emotionally repressed man. He was absolutely terrified of any sort of illness. I didn't have a good relationship with my father at all and as a result of his fear of illnesses, he didn't want anything to do with S He couldn't handle the fact that there was something wrong with him. This had a huge impact on our little boy, because subconsciously he knew his grandad didn't want to be near him. By stark contrast my father would look past S and make a fuss of our daughter GRO-B It is horrible to imagine the impact that this would have had on S For 10 years, from when S was the age of seven, because of the way my father was and how my mother was influenced by him, my parent's relationship with our kids was greatly affected. This caused the young S great confusion and anxiety and was yet another negative aspect to an already difficult existence when taking into account S condition, then treatment and his schooling, All of these things impacted on him hugely.

32. GRO-B parents could not have been better and they treated S in the loving and inclusive way one would expect. S adored GRO-B parents as they did him. Their relationship had a very positive impact on S

33. Around the age of 10, we took S to see a counsellor who's first question, directed at GRO-B not S sitting in the same room, was to ask what haemophilia actually was. When we came out of that first session I knew S would never go back. He was very disillusioned and as young as he was, recognised that the woman didn't even know what he had. S mental health went downhill dramatically from there and he began to be quite cynical, which for a boy of that age was not healthy. It was like a big black cloud that had continued to expand.

34. When it came time to think about S move onto secondary school, we were very careful in choosing the right school for him. We found a school about five miles away from home, which had the most amazing headmaster. When S began attending this school we noticed a slight uplift in his mental health and general demeanour. He could keep his Factor VIII, which he would take in a 'cool bag' each day, in a fridge at school. By this time at the age of 11, he was self-sufficient in administering his own injections. He was even allowed to go on a holiday with the school and was generally able to be a lot more independent. The school put the onus on him and this gave S responsibility and control - a say over his own life. This lasted for a couple of years, before the headmaster unfortunately left the school. Without his presence and influence, things deteriorated for S

35. Around the age of 14, S was refused by the school to go on another school trip. He was told out loud and in front of the whole class that he couldn't go because he was too much of a risk. He was so embarrassed and upset when he came home that day. We had also heard rumours that two teachers at school who were known to be in a relationship, were picking on S singling him out and showing him up in class.

36. S was beginning to have increased ankle bleeds around this time. I remember Sister GRO-B was quite worried about the amount of bleeds S was having, indicated by the excessive amounts of Factor VIII he was going through. She also believed S increase in bleeding episodes could have been stress related from what was happening at

school and she was prepared to go to the school to talk to them about it. In retrospect, while I believe S school life would have added to it, I now believe his increased stress was due to the conversation he had overheard at GRO-B Hospital and the stories and reports he was watching on the news. We just didn't know this at the time.

37. After this, although S engaged in group activities, he began to withdraw from a lot of things to do with the school. He continued to go every day, however he became more and more isolated.

38. In 1995 at the age of 16, a year earlier than is usual, S was able to drive due to his condition and DVLA mobility provisions. He passed his driving test and was able get a Motability car under the government 'Motability' scheme. This gave him a lot of independence and he began to drive himself to his hospital review appointments at GRO-B Hospital. It also made him a popular boy for a while, as he was the only one in his peer group to have a car.

39. One day after such an appointment he came home with some new medication. S told us that the doctors had said that "it was going to make him feel better", however we didn't know what he had meant by that. I have to say that it has been this aspect that has caused GRO-B and me the most difficulty in recollecting what happened. Quite some years later, we learned that the treatment was Interferon and Ribavirin, given to him because he had HCV. However, at the time that S had come home with it, we had no idea he was infected with HCV. Not only that but we don't know what the conversation was regarding this 'treatment'. We don't know if it was a trial or an established therapy. I can't remember if we knew at the time that a patient aged over sixteen is able to give consent, I suppose we must have, otherwise we would have questioned it. We were certainly not consulted; as I say, we didn't know S was HCV positive. It does now make us question whether it is ethical for a sixteen year old to consent to such strong therapy, without consultation with the parents. I would have thought that it would have been beneficial for the success of the treatment for us to have been

aware. If it was a clinical trial, I am sure that it is not right that S could have given his consent. To be clear, at the time we had no idea that this treatment constituted S first HCV therapy.

40. Within a day or so of taking this medication, I remember S felt absolutely horrible and he just kept saying how rough he felt. He walked straight out of the back door and threw the medication out into the garden. That was the end of that treatment. Given that S had said that it was going to "make him feel better" and it had had the opposite effect, I think we just thought that it didn't work and that was that but as I have stated this 'event' seems to be a 'black hole' in our collective memories.

41. With regard to S unbeknown to us at the time HCV diagnosis; to our knowledge, we do not believe S was provided with any information or advice about HCV and relevant infection control information.

42. The timing of this memory fits in with what was contained within a letter that was sent by our General Practitioner, Dr GRO-B to the Coroner for S inquest, held on the GRO-B 2018. Dr GRO-B wrote that S was diagnosed with HCV on the 1st September 1995. S would have been 16 years old and evidently wished to keep this from us at the time. I should point out that Dr GRO-B is a doctor at the practice that we use; he personally had not treated S but was the doctor chosen to write the letter to the coroner.

43. When S was about 17 or 18 he began to go out a lot drinking with his friends. He was drinking more than your average teenager and he would later tell us that the drinking would help to blank everything out in his head. Clearly, S was using alcohol to self-medicate. At his worst, he would be going out every night to get drunk. He became very aggressive and was angry and bitter about why he had to have haemophilia. Obviously by this time, we had no idea about the HCV but that must have

also been a factor. During this period S was caught drink-driving and banned.

44. S left school with no qualifications. S had always been good with his hands and had leaning towards things technical. He started to work for a communications/alarms business, which was owned by a friend, GRO-B who lived up the road. He unfortunately had to stop working there as he felt he was letting GRO-B down because of all the days he had to miss due to his bleeds. As such, we helped set him up his own small business and he went into alarms and security. This was perfect for S as he could fit his work in around his bleeds.

45. On the 18th May 2001, around the age of 22, S attempted suicide by pumping air into his veins with a needle. He had been drinking and did this deliberately and demonstrably right in front of us. He was taken by ambulance to GRO-B Hospital and, after a couple of days, was put on the psychiatric ward where he discharged himself some days later because he needed to drink. This was the first of numerous incidents that could constitute either genuine suicide attempts, or cries for help and attention by S Either way, it was extremely distressing that it had come to this.

46. While S may have been struggling mentally, he still had in him this drive to want to help others. In his mid-teens, he volunteered with the Red Cross and he would go to football matches with them to help out. His sister, GRO-B was a very good dancer and he used to love helping her with the lighting for her shows. He loved feeling part of something and being 'of use' to people.

47. In 2002, S moved to GRO-B where he did maintenance work for the hotel chain, GRO-B He then met GRO-B, who later became his wife. Together they moved to GRO-B and rented a house. They were not able to buy a house because S couldn't get life cover due to his haemophilia.

48. At this point in his life, S was not having treatment for his HCV. He was still drinking but nowhere near as much as he used to as since he had met GRO-B he was living a different lifestyle.

49. In 2008, GRO-B and S had their daughter, GRO-B and they got married in 2010 when GRO-B was 2 years old.

50. From what GRO-B and S have told us, in 2012/2013 things started to go downhill again. While living in GRO-B with GRO-B S was going to the GRO-B Hospital for his reviews however he wasn't getting along with the consultant there. S was 100% fixated on everything to do with haemophilia and he had heard about something that could help his ankles. I am unsure whether this related to a brace or medical support, however GRO-B wouldn't offer it to him. S decided to contact Professor Mike Makris at Sheffield Hospital to ask whether he would be happy to take over his care. Professor Makris was content to look after S and in their initial appointment he assessed everything, including having blood tests and liver function tests. After these tests it was discovered that S liver had deteriorated significantly and this had been completely missed by GRO-B Hospital. Professor Makris then put S on treatment for HCV. At this stage, GRO-B and I had thought that this was S first treatment for HCV.

51. When I talk about S HCV treatment I think in terms of him having two treatments because for so long we were unaware of the first, which he only took for a few days anyway. S had three treatments in all , but in my head, I still just think of the two. For the purposes of this statement, I will refer to S having had three treatments.

52. S second course of treatment for HCV, consisted of a 12-week course of Interferon and Ribavirin, commencing in April 2013. There were two main stipulations that S had to adhere to while taking this treatment. The first was that he had to be at least three months sober prior to beginning the treatment. S did this easily, he had an objective.

The second stipulation was that he had to take antidepressants for three months prior to beginning the treatment, as once he was on the treatment it would likely have an impact on his mental state. Our understanding of this was that by 'pre-loading' antidepressants into S system, it would help him cope with the 'downs' that it was anticipated would come with the HCV therapy. We don't know if this was decided because of what had happened the first time or if they had learnt more about the effects of the treatment by this stage.

53. While on this treatment for HCV in 2013, S went through a very low point in his life, probably a mixture of his own state of mind conspiring with the Interferon and Ribavirin. It was horrific for GRO-B and GRO-B and it was extremely hard for us too.

54. Every few weeks to a month S would be self-harming by cutting his arms and letting himself bleed uncontrollably. At some point afterwards, he would take the Factor VIII to stop the bleeding.

55. On another occasion, I was at S and GRO-B house in GRO-B S had disappeared, and when I went and found him in the back garden he was pouring petrol over his head. He took a lighter out of his pocket and there was a big panic whereby I took the lighter from him, while GRO-B trained a hosepipe on him to wash the petrol away. S refused to go to the hospital and we got him showered and cleaned up at home. His demeanour was very down and, of all the incidents, I felt that this was the one that maybe he actually wanted to carry out.

56. On at least three occasions S swallowed handfuls of various pills of the numerous tablets that he took as part of his medication. He always did this along with drinking a lot of alcohol. He never went to hospital after these incidents, and we had always managed to stop him before he had taken too many, though his intention was to have taken more. I know that GRO-B also had similar experiences with him.

57. There was one occasion when GRO-B and GRO-B were with us in GRO-B S stayed at home because he was suffering the effects of his HCV treatment and he insisted that GRO-B and GRO-B came to see us. S sent GRO-B a photo of a noose around their stairs at home with him standing next to it. GRO-B spoke to him on the phone and then made her way home to GRO-B and I followed in my car. When we arrived, he was psychologically in a very bad place. My belief on this occasion is that he never intended to take his own life, and it was a cry for help.

58. It was a truly awful time. I would often stay with S for days, monitoring him, and he would sit in the corner of his room with his head in his hands and not say a word for hours. It was heart breaking what had happened to him and how it was continuing to take him in a downward spiral.

59. Our relationship with S at this stage was very strained. We were always there for him and we would never walk away but it was very hard on both GRO-B and me.

60. As a result of these incidents and the side effects of the HCV treatment, after discussions with the hospital, after nine and a half weeks of the twelve-week treatment, S was withdrawn from the therapy. This was tragic, as S liver function tests indicated that the treatment was working and that the HCV was nonvisible, however once he stopped the treatment his HCV came back. S was devastated at this news and he blamed himself for not being able to last the full 12 weeks of treatment. This exacerbated the down ward trajectory of S mental state. He would always tell us how terrified he was of staying in the hospital because he never thought that he would come out - "other than in a wooden box". You can only imagine the devastating effect that this kind of talk would have on GRO-B and me. I say this not out of self pity or to gain sympathy for us but to demonstrate the depth of despair that S had sunk to, how we felt for him and of course the impact of this on his family.

61. After the suicide attempt involving the noose, Professor Makris referred S to see a psychiatrist who told S that he had been put on the wrong medication for the anticipated 'depression' during his treatment. He told him that if he had come to him he would have put S on antipsychotic drugs instead of antidepressants, which would have allowed him to finish his treatment. This news absolutely destroyed S He felt like after putting his whole being into clearing his HCV, after being given this opportunity and he'd been prescribed the wrong treatment to assist him to do this. He had also been told that he will only get two chances at the HCV treatment and at this point in time he wasn't sure whether they were going to take into account his 'first' HCV treatment, the one he had gone on for only took for a few days as a 16-year-old. This compounded S inner trauma.

62. During this horrific time, GRO-B had to change her career as a result of S not being able to work due to sickness. She gave up her job as a nursery nurse, and became a self-employed parcel courier, picking up people's online orders and delivering them to people's homes in her car. This meant that she would have the flexibility of being able to collect her parcels from the depot while GRO-B was asleep at home with S and then deliver them later when she could.

63. Professor Mike Makris from Sheffield Hospital had discussions with S about him needing to give up alcohol and the danger of drinking with HCV. S knew alcohol was having a detrimental effect on his liver however he often used it as a way to 'escape'.

64. In April 2017, Professor Makris recommended a new treatment to S Sofosbuvir. This was a 24-week treatment and only a limited number of people were allowed to have it. S had to fit into certain criteria and it had to be signed off by two or three hospitals before he could start taking it. We were told that it was a brand-new treatment and results were not guaranteed, however it didn't have depression as a side-effect, unlike Interferon and Ribavirin. The side-effects it did have though were still

awful; S suffered from lethargy, flu like symptoms, diarrhoea, hallucinations, incontinence and severe bleeds from the mouth and rectum. Because his blood platelet count was very low, S was put on Romiplostim, which made him horrifically ill. In terms of S drinking, he told us that he didn't have to be alcohol free. I am unsure if this was as a result of any medical advice. If it was this is regrettable, as it effectively gave S the go ahead to continue drinking. During all of this though, S was very diligent with his Factor VIII treatment and he never once refused it.

65. While on Sofosbuvir, S white blood cell count became dangerously low. He was too sick to get to the hospital, so a nurse had to go to his house to take S blood. Because of his low white blood cell count, the nurse would have to wear masks and gloves as S immune system was virtually non-existent and so he was susceptible to infections, thereby putting others at risk. GRO-B would move backwards and forwards from their place in GRO- to stay at her mother's just around the corner, for GRO-B sake. There was phenomenal pressure on the whole family during this time and S became even more reclusive.

66. S was on Sofosbuvir from April to October 2017 and he was 20 weeks into the 24-week course when the doctors decided to stop the treatment due to his dangerously low white blood cell count. Throughout the first 20 weeks, tests had showed that S had cleared his HCV, however Dr Armstrong at Birmingham Hospital subsequently told us in May 2018, that it had come back again.

67. After this abandoned treatment, S was seriously ill and so was in-and-out of Birmingham Hospital until November when he was admitted for a longer period until just before Christmas when S called GRO-B and told him he had been diagnosed with liver cancer. We knew this had been a risk as they had discovered some nodules on his liver, however we thought they were being monitored and were ok.

68. In January 2018, S was put on the liver transplant list. To be on this list, S had to have psychological assessments and he had to give up alcohol completely. As part of the assessment, the family had to be involved so that we could support him with this. GRO-B had to have a phone interview with the hospital as they wanted to make sure that the conditions at home would ensure every success for S new liver to thrive.

69. At this point, S had moved back in with us in GRO-B so that we could provide the necessary care for him and GRO-B could continue to look after GRO-B Due to S failing liver, fluid and waste in his abdomen called ascites, was not being filtered through properly and so he would get a huge distended stomach, completely disproportionate to the rest of his body. Every so often we would have to take him to the Queen Elizabeth Hospital in Birmingham, to get this drained. On one occasion, a few weeks before he passed away, when we went to see him in Birmingham, the doctors drained 18.5 litres from his body, having already drained 5 litres a day before.

70. Throughout this period, S was on and off the liver transplant list as he would often contract an infection due to his low white blood cell count. In March 2018, when the "Beast from the East" snow storm hit the UK and the weather was atrocious, we received a call at midnight to let us know they had a liver for S We had to go to Birmingham; GRO-B always made sure the car was full of petrol and S would diligently have a packed bag waiting by the front door for when the hospital called with news of a new liver. On this occasion, we got half an hour down the road, through the snow, when the hospital called us back to say that unfortunately the liver was not suitable for S No reason was given, they don't tell you why. It could have been for one of many reasons It was devastating, for S especially but for the whole family too.

71. As time went on, S optimism began to subside and his determination at being ready to go at a moment's notice, began to diminish. His breathing became horrendous, extremely laboured, his

body kept filling up with fluid and waste and he was covered in the most phenomenal stretch marks.

72. In April 2018, S decided to buy himself a manual wheelchair. At first, he would be very reluctant to go anywhere, so reclusive had he become. However, eventually we were able to convince him to go out for short walks or to the town centre and we would stop at Costa for coffee, something that I liked to do. S couldn't see the point at first but within a few weeks it would be S that would be pestering us every day to go out GRO-B, GRO-B, when they were over S GRO-B and I would go out for walks together. He loved it so much and delighted in being able to do something with GRO-B. He just loved to watch her. After these afternoons his face was pure joy, it was so lovely to see. Given what was to come, these were happy occasions and memories that we treasure.

73. During this period, we would receive seemingly random but very welcome phone calls every few weeks from either Dr Percy, Mr Naggar or Dr Gillian Lowe, from the Haemophilia Centre at Q.E. Birmingham Hospital. Dr Lowe was the head of the Centre. They would ring to check up on S and would ask to speak to him directly. This was thoughtful and indicative of the way that the Queen Elizabeth treated S We thought this was wonderful.

74. From around February 2018, S was on 21 different medications. Some he took daily, or more than once a day, and some he took every other day or less frequently. These medications were for multiple medical conditions and complications including pain relief for problems he was having with this back. S would get frustrated with the regime of having to take all of these medications.

75. On Sunday GRO-B 2018, S was struggling to get up the stairs to bed. This wasn't uncommon, as due to S weight gain combined with his muscle wastage, he would often take a long time to get up the stairs. He also had difficulty breathing and the exertion made this worse. Either GRO-B or myself would walk behind him just in case. But this night it

was different, S was really struggling. I was desperate to take him to the Birmingham Hospital, however they didn't have a bed available for him and they said he would have to wait in A&E there.

76. Eventually we managed to get him into bed at home and I remember asking him to promise to call out at any time in the night if he got any worse. He gave me permission to call 999 if his condition deteriorated during the night.

77. In the morning, I went to check on S and his eyes were open but he wouldn't or couldn't talk, he would only stare vacantly. I held him close to me and I called Birmingham Hospital again. They told me to dial 999 immediately. I didn't want S to go to our local A&E at GRO-B Hospital due to past negative experiences there, however the Haematology Centre at Birmingham Hospital assured me that the ambulance would take him to GRO-B Hospital, where they could then stabilise him and then transfer him to Birmingham.

78. I went with S to the hospital while GRO-B waited back at home to make the necessary phone calls and to be the point of contact for GRO-B in GRO-B me at GRO-B and Birmingham Hospital.

79. During the journey in the ambulance Dr Gillian Lowe rang me to promise me that they were doing everything they could to help us. They were liaising with the GRO-B and S had all the Factor VIII he would need. It was very comforting to hear from her during that time.

80. Once we got to the GRO-B Hospital the doctor who was looking after S came up to me and questioned very rudely and authoritatively why we had brought S to his hospital. He said he was far too complex for them and they didn't have a Haemophilia Centre. With tears streaming down my face, I said that Birmingham Hospital had told us to bring him here. It was absolutely awful, being spoken to like that while my son was so clearly so desperately unwell. The GRO-B Hospital made so many mistakes in S care during that time; they took his bloods and then

they lost them so they couldn't provide the results to Birmingham and they were leaving his PICC line, a canula used for long-term use of medications and frequent blood draws, blocked with blood. This really worried me as S PICC line was how he was being administered his Factor VIII medication, and that was his lifeline. The nurse then wanted to use Heparin, an anti-coagulant and blood thinner, to unblock it, which is the worst thing you could give to a haemophiliac. I didn't feel like I could leave his side even for one minute as I was constantly worried what they might do next. As a whole they were grossly incompetent, in my opinion and I take no pleasure in stating that this validated my fears about going there in the first place.

81. That night, Monday GRO-B S stayed on the Acute Surgical Unit (ASU) at GRO-B Hospital and this was when he lost consciousness. From that point on there was no response from him. However, regardless we would continue to talk to him.

82. Birmingham Hospital still did not have a bed available for him and so on the GRO-B he was moved to the Intensive Care Unit (ICU) within GRO-B The ICU were fantastic with S They acknowledged to us that they were out of their depth, however they did everything they could in liaison with Birmingham. The compassion they showed was very comforting during that time. GRO-B and GRO-B arrived in GRO-B on the Monday that S was admitted into GRO-B At first, a nurse wouldn't allow GRO-B in to see S which left her distraught. After we'd spoken to the nurse to explain to her what GRO-B had gone through with S and the things she had seen, the nurse allowed her into his room as long as we were okay with it. GRO-B was so happy once she was in the room with S she just held his hand and comforted him.

83. On the evening of Wednesday GRO-B S was conveyed the 100 or so miles to Queen Elizabeth, Birmingham in an ambulance on blue lights. His heart and lungs were failing, every part of him needed support and upon arrival he was placed on the High Dependency Unit (HDU).

84. GRO-B and I followed the next morning on Thursday GRO-B and we spoke to the doctors and nursing staff who were all very good. GRO-B went to visit S on Saturday GRO-B and took GRO-B in on the Sunday. That Sunday GRO-B, a doctor told us the S was gravely ill, however they were doing everything they could to get him back onto the ward. We all stayed in a local hotel through this period.

85. On Monday GRO-B GRO-B and I, GRO-B GRO-B, our daughter GRO-B and her partner were all there at the hospital with S Dr Armstrong and another doctor took GRO-B GRO-B, GRO-B and me into a side room, this was not a good sign. GRO-B partner took GRO-B away to keep her occupied. They told us that S had made no improvements since he had been admitted on Wednesday GRO-B At one stage he needed major oxygen support. They had given his vital organs all the support they could and they had found a small bleed on the brain, which would have been catastrophic if it was to become worse. GRO-B asked them to confirm what they were suggesting and they told us that S had a zero chance of survival and the kindest thing would be to slowly turn off all his various supports. We spent a long time asking all the obvious questions and we were told to take the night to think about what we wanted to do. That was the longest night of my, our lives. We didn't get any sleep knowing that when we woke up the next morning we would have to watch our son die. The decision was ultimately taken by all of us as a family, though with GRO-B being S next of kin, she would have had the final word. That said, we were in full agreement.

86. On the morning of Tuesday GRO-B when we arrived back at Birmingham Hospital, Dr Armstrong came straight to see us. He assured us again that there was no chance of S surviving and we all finally decided what S would have wanted and we gave consent to turn off his life support.

87. That afternoon, they put S in his own side room with nurse specialist Kelly Naylor. She explained to us all what would happen and it was all

very dignified. The whole family sat around talking to S as we were told the last thing to go would be his hearing. GRO-B had spoken to GRO-B about what was going to happen.

88. Kelly was so fantastic with GRO-B, who was 10 at the time. She painted both S and GRO-B hand and placed them together on a canvas so that GRO-B can always have an imprint of her daddy's hand. She also cut off a lock of S hair for her to keep. All the while, she was talking to GRO-B, asking her questions about what she used to do with her Daddy and that she should keep telling her Daddy what her favourite things were.

89. The process of turning off the machines that were keeping S alive was commenced at around 2pm. The gradual removal of S support was indicated by the descending numbers on the monitors that S was connected to. It seemed to take so long considering that we had been told that S was being kept alive by these machines. At around 4.40pm, S passed away. Kelly came to us and suggested we went to get some fresh air while she prepared the room, removing all of the tubes and wires that S was connected to and put the machines away. When we came back S had been cleaned up and there was no evidence of the medical paraphernalia that had previously been around him. He just looked so peaceful as he lay there.

90. As S had died at a Birmingham Hospital, there was going to be an inquest into his death. We stayed one more night in Birmingham so that we could collect the relevant papers the next morning. That morning, Wednesday GRO-B, GRO-B and I went and saw S in the morgue and we stayed with him for a while, saying goodbye. He looked so peaceful and 'free' of all the horrendous stresses and strains of his health problems. We then drove home that afternoon. S funeral was on the GRO-B, exactly one month later.

91. On S Death Certificate, the cause is recorded as:

I (a) Multiple Organ Failure, (b) End Stage Chronic Liver Disease Secondary to Hepatitis C and Hepatocellular Carcinoma.

II Haemophilia. Beneath the cause of death.

It states 'Conclusion: Death as a consequence of viral infection from blood products'. I exhibit S death certificate as WITN0477002.

92. S inquest was booked for GRO-B 2018 however it had to be changed to GRO-B as the doctor was going to be away on holiday. GRO-B contacted the coroner's office to ask if the date could be changed as that was the first day of GRO-B GRO-B and we were very keen to go. We were told by an official that there was no way to change the date. We found this very upsetting as we wanted to be at the first day of the Inquiry to represent S When we went for the inquest, the coroner told us that we definitely could have changed the date and she was terribly sorry that we were told otherwise. Obviously by then it was too late.

Section 3. Other Infections

93. To my knowledge, other than HCV, S received no other infections as a result of being given infected blood products.

Section 4. Consent

94. From our recollection, the only time when S was maybe treated without proper consent was in 1995 when he was 16 years old and came home from his review appointment at GRO-B Hospital, with treatment for HCV. I don't think he was of an age that he could consent if, as I believe it may have been, a clinical trial. If it was a bona fide proven HCV treatment, then maybe S consented to it, which may have

been technically lawful but I would question whether it was ethical, given the strength of the drugs and their horrendous side effects.

Section 5. Impact

95. I carry with me an enormous amount of guilt over what happened to S and this impacts upon me greatly. After everything that we as a family have been through, it may not be a rational thought but I blame myself for S Haemophilia, because it came down my family line. Although I didn't know about it, I always felt responsible for it. On a bad day, S would often get very angry at me and take it out on me. He would accuse me that it was my fault he had haemophilia and he would yell at me that I gave it to him. This was very hurtful and traumatic. S would always apologise to me and give me a big hug once he had calmed down. This was the frustration and injustice that he was feeling.

96. I also feel guilty that it could have been me who administered the infected Factor VIII. We were never definitively told when S was infected with HCV or what the batch number was, if indeed that could be ascertained.

97. The stress of constantly being worried about what might happen to S hasn't left me yet, even well over a year after he passed away. 'It' was such a dominant part of our lives. We were always alert to anything that might happen. It didn't matter the circumstances, whether he was with us or not. The phone may ring at any time – it could be GRO-B, if S wasn't with us or the hospital when he was on the transplant list. Even now, when we are out and hear a phone ring that sounds familiar, we react, it's very stressful. I don't think we realised going through those years just how all-encompassing it was.

98. I have been completely traumatised by all of S suicide attempts. I personally witnessed 3 overdoses, the occasion when S poured petrol over his head, when he pumped air into his veins, the cutting of his arms

and when he attempted to take his car keys from me as he said he intended to drive at speed into something solid. I had to really struggle to hold onto the keys to stop him taking the keys from me.

99. The impact of S numerous and complex medical conditions impacted on GRO-B and I greatly. When he was admitted into hospital we knew he was being cared for and this gave us a few days of respite, depending on how long he would be in hospital for. We didn't have a social life during that time, we never went out because we were always caring for S and effectively 'on call'. During the later months, we had to be near S with the car ready 24 hours a day, just in case we received a call from the hospital about a new liver for S

100. Since we lost S we walk every day. It is very therapeutic for us, however we still feel like we're in a rut. GRO-B talks about how he used to be so quick to fix anything that went wrong with the house but now everything seems like an effort and it takes him ages to finish things. His whole life since S was diagnosed with haemophilia has been a life of worry. Now there is a massive hole that has been left, not just that we no longer have our beloved son but the void left by everything that surrounded him and his conditions.

101. My feeling is not that S is at rest now, he's just not suffering anymore. The amount of pain, anxiety and stress he went through while he was living was beyond what anyone should have to bear. I can't yet come to the feeling that he is finally at rest.

102. We went to a bereavement counsellor and we also spoke to a lady at the Red Cross who was at the Infected Blood Inquiry during the Oral Hearings. We ended up speaking to her for over an hour and a half. We came away from that feeling quite good and she told us that she didn't think counselling would be beneficial to us as we're currently doing everything that she or a counsellor would recommend us do. Listening and speaking to other infected and affected witnesses at the Inquiry Oral Hearings has been very helpful too. It is a comfort to speak

to others who has been through similar experiences. There is an understanding.

103. The Infected Blood Inquiry Preliminary Hearings began GRO-B S GRO-B and I have travelled to watch hearings in Leeds and in London. It's never far from you. You hear stories in the news and you can relate to a lot of them. While you're trying to move on, it doesn't take long to bring up all of those painful and unpalatable feelings and memories.

104. There has been a large impact on both GRO-B and GRO-B having to live through S condition and his death. I feel GRO-B is suffering from a form of attachment disorder. In July this year, I had to go to hospital because I was suffering from a Urinary Tract Infection, which they didn't know at the time. We let the family know what was happening and GRO-B was so concerned that she insisted her and GRO-B travel from GRO-B to GRO-B so that she could be with me. When they arrived, she stuck by my side all day and had to be pulled away just to get something to eat. This is an indication of the impact it's had on GRO-B. After losing her father, she is so concerned that something bad might happen again every time anyone gets ill. I know GRO-B thinks and worries far more than is normal for an 11-year-old due to what she's gone through and what she's seen. She is not old enough to give evidence herself so I would like to make that point in my own statement.

105. GRO-B has told me that she constantly experiences feelings of devastation, anger and bitterness. She feels that HCV took away the man she'd first met. S used to love doing jobs around the house and going out and doing things with GRO-B. When GRO-B was born, S was the proudest man alive. As S condition progressed though, he began to change. It was so hard on GRO-B and GRO-B to watch S go through all the pain and the treatment that he had to endure. I know that S took out some of his frustrations on GRO-B, as he did with me. GRO-B social life and interactions outside of the family was also impacted by what S was going through. She didn't like to leave S

on his own but S wouldn't go out because he was self-conscious about his appearance and didn't want to be seen. He was a total recluse and preferred to stay indoors with the curtains closed.

106. GRO-B also feels completely traumatised by all of S suicide attempts and his hallucinations, which were very scary. She says it is horrendous having to watch GRO-B grow up without her dad and she finds it really tough to see GRO-B friends interacting with their Dads.

107. GRO-B is represented by a law firm who also previously represented S She intends to give a statement but up until now she has been unable to do that due to her grief. I would like to add that losing S has had an enormous consequence other than the obvious such as loss of a life partner and the financial impact. S handled all the administrative household issues that GRO-B didn't have the confidence, or felt hat she didn't have the ability to deal with herself. This is a practical example of the impact losing her husband has had on her, I point this out in case she never gets to provide her own statement. There will be so many other things that she would say, that maybe we don't even know about.

Section 6. Treatment/Care/Support

108. After S had to stop his second treatment of HCV early, he was phsycologically in a very bad place. He was drinking a lot and attempted suicide multiple times. Around this time, I took S to the GRO-B Rehabilitation Centre in GRO-B which is a rehabilitation unit for people who desperately wanted to get off alcohol. S had an assessment and the Centre were prepared in principle to take him on, however they weren't able to provide us with a definitive offer due to the complexity of his condition. They did suggest that if the liver unit at Sheffield Hospital were willing to provide support to S and this would have been a substantial amount of support, then they could accept him. Unfortunately, Sheffield Hospital wouldn't agree to it. This was quite

upsetting, as GRO-B and I felt that being at the Rehabilitation Centre would have helped S considerably at that time by weening him off the alcohol. He would have also been surrounded by people who he could relate to and who were going through similar situations.

109 GRO-B and I have never been offered counselling and to my knowledge, S was never offered counselling relating to his HCV infection either.

Section 7. Financial Assistance

110. From a financial point of view, we never received or sought any financial assistance. After S passed away the medial professionals that we spoke to were astounded that we never had any professional medical assistance at home with S considering the procedures and complexity of care we had to give him. We never even considered asking for this, as we just did what we thought any parent in our situation would do.

111. I am aware that S received payment from the Skipton Fund and I understand from GRO-B that he may have received what she called a Stage 2 Payment. He was getting quarterly payments from the Skipton Fund. I believe he was also in receipt of income support particularly as GRO-B was the sole earner in the family and he was also received mobility allowance due to his haemophilia.

112. I understand that GRO-B received a £10,000 lump sum payment from the Skipton Fund for GRO-B when S passed away.

113 S death was devasting for me and my family and I am writing this statement as I wish to act as a voice for S to ensure that something is done and individuals or organisations at fault, are held responsible. I

want this Inquiry to uncover the truth and to bring about justice for all those who are currently suffering and who have suffered.

114. As I alluded to earlier within this statement, our grandaughter, S daughter GRO-B, can't give her own statement. However, knowing that I was being visited by people from the Infected Blood Inquiry, she had the thoughtfulness and presence of mind on her first day back at school after half term, to send me a text message before I gave my statement to the Inquiry to make sure I was ok and later she sent another message, asking how it went. After I replied to her she responded with a message (for those from the inquiry interviewing me) that I would like to end my statement with, exactly as she had written it. GRO-B wrote:

"I am really upset because I don't have my daddy anymore and it is really hard for mummy because she has to try to be daddy and her self. Also, I am really angry and I don't have my daddy anymore and I miss him really badly and I wish he could come back.'

Statement of Truth

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

Signed GRO-B

Dated 28·11·2019.