Witness Name: GRO-B
Statement No.: WITN3218001
Exhibits: WITN3218002 – WITN3218009
Dated: 30 April 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows: -

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B 1950 and I reside at GRO-B I retired in 2017, just after my husband, GRO-B retired. I trained as a teacher but after GRO-B: S death I did not go back into teaching due to the stress of his death. I was involved in volunteer work, and then worked as a teaching assistant and learning support in a school. I then moved to the GRO-B GRO-B first as a volunteer and then as a part-time paid employee.

2. I got married in GRO-B and I had two children together; our daughter, GRO-B was born in 1981 and our son, S was born on GRO-B 1983. This statement is in relation to S s death. I make this statement from my recollection of events. We have recently received copies of S s medical records and will provide further information to the Inquiry, as necessary, when we have been able to review the records. GRO-B has also made a statement to this Inquiry GRO-B Our recollections of the events leading to S s death are very similar.

Section 2: How affected

3. GRO-B worked in engineering and frequently travelled for work. We moved to GRO-B in 1980 as GRO-B was working in the GRO-B We were still living in GRO-B when our children were born in 1981 and 1983 respectively.

4. We realised that at a relatively young age, around the time S began to crawl, that he had a problem as he was frequently bruising severely and extensively. We were concerned something was wrong and so we took him to a hospital in the GRO-B where he was diagnosed with mild haemophilia A initially. Doctors at the hospital had very little experience or knowledge of haemophilia.

Haemophilia

5. Initially, in GRO-B we were told that S had mild haemophilia. We returned to the United Kingdom ("UK") in 1984 on leave, and S was seen at the Royal Free Hospital ("Royal Free").

6. Following this visit to the Royal Free, S was diagnosed with severe haemophilia A with a clotting factor of less than 1%. I later underwent testing to confirm whether I was a carrier of haemophilia, which was confirmed positive in May 1988. I was told that this was a result of a mutation when I was conceived. The whole family was tested at the Royal Free to confirm the history of haemophilia in our family. It was discovered that, before me, there was no history of haemophilia. GRO-B is believed not to be a carrier of haemophilia.

Factor VIII Treatment

7. GRO-B returned to the UK in January 1984 to attend a funeral. He contacted The Haemophilia Society and they suggested we go to the Royal Free with S We took S to the Royal Free on our home leave in April 1984. The Royal Free provided us with some NHS Factor VIII to take back to GRO-B

with us as this was considered to be the best and safest treatment available for S

8. Based on the way it was described to us, it seemed NHS Factor VIII was a good idea. We took some NHS Factor VIII back to GRO-B for use while we made arrangements to return to the UK where we believed we could get better treatment for S We understand that S was either infected by that Factor VIII or treatment he received shortly after we returned to the UK to live.

9. We had no previous knowledge of haemophilia. The Royal Free took considerable time talking to us about S s condition. However, it was a steep learning curve for us; unfortunately, we were not always seen by doctors who were knowledgeable about haemophilia and S often suffered unnecessary pain because the doctors did not recognise that S had a bleed. When visiting an actual haemophilia centre, we always had good treatment but we lived far from a designated centre

10. I did not know anything about HIV or AIDS at that stage and in fact when I did mention it, I was told not to worry about HIV. We were told it was best to treat S with NHS Factor VIII. We accepted the advice given and believed that we were being given the best advice – we had no experience of haemophilia to draw on at this stage and were grateful that there were doctors who were experienced in treating the condition.

11. When we returned to GRO-B it became clear to us that we could not get the same treatment for S s haemophilia in GRO-B compared to the treatment available in the UK. In GRO-B the doctors we saw had little experience of treating the condition. In fact, on one occasion, S nearly died when a blood sample was taken from the femoral artery and S continued to bleed. GRO-B informed his employer in April 1984 that we wanted to move back to the UK, so that S could obtain better medical care. We moved back to the UK in August 1984.

12. When we returned to the UK, we were living in GRO-B This meant that S had regular review meetings re his haemophilia care at the Royal Free, but that his day to day care and treatment was through our local hospital, James Paget (University) Hospital ("James Paget"). When we returned to the UK, S continued to have Factor VIII treatment. We were given information on how to mix the Factor VIII and the correct way it should be used.

13. Initially, we had to go to hospital for them to administer the Factor VIII to S We commenced home treatment with the product in 1989 and we were taught how to administer it at home. If we were particularly concerned, though, we would still take S to hospital. S was therefore being treated with Factor VIII from 1984.

14. At the end of 1998, we worked with S s consultants to produce a summary of some of the more serious infections and illnesses that S suffered following his infection with HIV and that are referred to within this witness statement, in order to clarify the dates of his illnesses and the treatment he received. This synopsis is exhibited at WITN3218002.

Diagnosis with HIV

15. By February 1985 S was receiving heat treated Factor VIII. By then the problem with contaminated blood seemed to have been more widely known

and heat treated factor was becoming available, which suggests that S was infected prior to February 1985.

16. In December 1985 we were informed that S was HIV positive. This diagnosis was given within 18 months of S first receiving Factor VIII. We received a letter in the post on 18 December 1985 from Eleanor Goldman [WITN3218003]. The letter said S had had some tests and Dr Mitchell at the James Paget would be contacting us with the results. In fact, we guessed what he had to tell us because by this time there was much horrific reporting of HIV in the press. I rang Dr Mitchell on receipt of the letter and he agreed to see us that day and told us that S was HIV positive.

17. We were told it was likely S became infected when we returned to the UK in August 1984 or shortly thereafter. It was believed that S had been infected through NHS Factor VIII treatment. At a later date, I am sure that we were told the batch number of the infected factor, but I cannot now find that information. At the time, we were struggling to provide care and support for S and trying to keep life as normal as possible for our daughter, GRO-B who at a very early age had to cope with the many traumas and many hours in hospital while S eceived treatment.

18. We had a good relationship with Dr Mitchell at the James Paget and he was always generous with his time with us and treated us with respect, discussing S s treatment with us. We felt we could always discuss S s treatment with him. In fact, I believe that our consultants at the Royal Free, James Paget and later at Addenbrookes Hospital ("Addenbrooke's") always had S s best interests at heart. Although with hindsight, we all made mistakes. On advice from the Royal Free, we did not tell S and GRO-B about S s HIV diagnosis at the time because we were advised they were both too young to know and also I believe that living with HIV and AIDS was not well documented at that time.

19. S s HIV became a much bigger problem than his haemophilia due to the significant number of infections he contracted following his HIV diagnosis. We tried to carry on as normal despite the number of hospital visits. All of the infections have merged into one big horror story, but I have set out in this statement the significant infections that I recall, following S s diagnosis with HIV.

20. S continued to be treated with Factor VIII following his diagnosis with HIV. In 1986, he had thrombocytopenia and was given steroids for that. S then had a splenectomy at the Royal Free in March 1989 as the steroid treatment was not proving effective. At the time, it seemed that this

was the best way forward and this was the treatment that his consultants advised.

21. It was after [redacted]s splenectomy that he was put onto prophylactic Factor VIII treatment, which made a huge difference because he had fewer bleeds and meant he missed less school. However, later he also developed problems with inhibitors to Factor VIII.

22. The doctors told us [redacted]s HIV had progressed to AIDS in April 1991. At this time we were taking [redacted] to James Paget for day to day treatment and he continued his reviews at the Royal Free. [redacted] commenced Azidothymidine ("AZT") treatment in May 1991 after we were told his HIV had progressed to AIDS. We knew that the AZT treatment could only slow down progression of AIDS; it could not cure it and it could not reverse the effects of HIV he had already experienced.

23. We suspected the HIV virus was beginning to affect [redacted] both physically and mentally. He was not growing well and eventually he was given growth hormones and this at least helped to appear more normal in his physical development. [redacted] was also frequently tired, with limited energy and this severely affected his schooling and his life generally [for example, see the letter at WITN3218004]. Psychological testing at the Royal Free showed that the virus was affecting his brain and our very bright son was now struggling to keep up with his peers. The psychologist's report showed that over the period 1989-1994, [redacted]s cognitive profile had altered substantially [WITN3218005]. His full scale IQ had reduced from 139 in 1989 to 114 in 1994. The psychologist wrote in 1994: [redacted] *is himself very worried and frightened by his loss of control over himself and he is also in need of help in understanding what is happening to him and support and help during this increasingly difficult time."*

24. As the number of infections increased, we dealt with the symptoms on a case by case basis. The doctors also seemed to be becoming more concerned. In

particular, at one stage I recall that he contracted tuberculosis. He started immunoglobulin therapy in 1992, which would take place on a monthly basis.

25. Sadly, despite a succession of different medications and interventions, the HIV virus continued to affect him. He was no longer able to swim competitively, play football or run around. We were fortunate that he found that he enjoyed table tennis, which required less physical energy. GRO-B used to take him to competitions, which he enjoyed, and I think it kept his mind off his other limitations in sports.

26. We did not tell S and GRO-B about the diagnosis until approximately 1994. As I have said above, at the time we found out about his HIV diagnosis in 1985, we felt that S was too young to be told. However, when S was 11 years old, we went to the Royal Free for a review and they suggested that we tell both S and GRO-B GRO-B would have been 13 years old at the time. I recall S was very ill then. He was having serious allergic reactions to many antibiotics but an increasing number of infections. We were grateful then for our good relationship with Dr Mitchell who would talk each infection through with us. We made the very painful decision that every effort would be made to sustain S s life but should he die there would be no CPR. This decision was reviewed with us on a regular basis.

27. At this time, the doctors and ourselves were concerned about the quality of S s life. Quality became more important than length of life. We wanted to keep him comfortable and still try to manage the infections as they came. He suffered from severe lethargy and this limited what he was able to do

28. On one occasion around this time I recall that Dr Mitchell was not available, and the staff at the hospital just kept giving S painkillers because he was in terrible pain. They would not give him Factor VIII. S said to me "*I'm just such a mess.*" I had no choice but to telephone Addenbrooke's and they said "*what are you doing, you need to bring him here.*" So we took him to Addenbrooke's where it was determined he had a bleed in his spine.

Addenbrooke's gave him Factor VIII, which resolved both the bleed and the pain.

29. In 1995, we were told that S was at the end stage of AIDS and he was extremely ill. Because of this, Dr Mitchell did not consider it was beneficial to continue giving him the large volume of medication he was taking at the time and in any case, S was unable to swallow all the medication. In fact, the temporary removal of medication resulted in an improvement in S s immediate condition.

30. S continued to have infection after infection and often had high temperatures that were very debilitating. However, S s health improved sufficiently to allow him to start a course at the local further education college. I took him and collected him from college.

31. In 1996 S had a liver biopsy that showed sclerosis scaring. He frequently suffered opportunistic infections which he contracted due to the effect of AIDS on his immune system. He was also becoming increasingly allergic to numerous antibiotics, possibly because he was being treated with so many for so long. This meant the choice of antibiotics he could be prescribed became very limited [WITN3218006].

32. S developed significant liver problems and the fluid build-up made it look like he had a "beer belly". S had cirrhosis of the liver and hepatitis C. Towards the end of his life, he had a series of transient ischaemic attacks ("TIAs") and he had an abscess on the back of his head. The abscess was drained under general anaesthetic but unfortunately S fitted while the effect of the propofol was wearing off.

33. There was a whole succession of illnesses and health problems that he had to suffer during the period of 1996 to 1997 which, if the infection could be identified, the doctors would treat with a specific antibiotic, providing S

was not allergic to it. Sometimes, the infections could not be identified and he would be treated with a broad spectrum antibiotic.

34. Despite all of these setbacks and illnesses and having missed almost all of his secondary education, S went to the local further education college in 1998 and he completed an IT course in summer 2000. We had a family holiday that summer in 2000 and S had hoped to start an IT course at the University of GRO-B Sadly, he died before he was able to commence his University course.

35. I remember very clearly the day S died GRO-B 2000. At 11.00pm on the night before, he seemed very well and he was sitting in bed eating a sandwich. We had had a good day. He had driven us to the cinema – he was very excited about learning to drive - and he was in a good mood. The next morning, S woke up with a raging temperature, which was not unusual for him; we had been monitoring his temperature for a number of years and it seemed as though he was starting yet another infection.

36. I soon became concerned that S s condition was deteriorating rapidly and so quickly that I needed to call an ambulance – usually I would call the hospital and then drive S to the hospital myself. He collapsed before the ambulance got to us.

37. The ambulance arrived within a few minutes of S collapsing and I went with S in the ambulance. We were taken to the James Paget. When we arrived at the hospital, the emergency team were already waiting for us. At the hospital, they sought to resuscitate S Unfortunately, they were unsuccessful and we made the decision to stop resuscitation. By 11.00am our beautiful son was dead. It appeared as if his whole system had just closed down.

38. I think I called GRO-B and asked him to come to the James Paget, although he believes it was someone from the hospital that called him.

39. S s death certificate stated cause of death as 1a) respiratory failure; 1b) pneumonia; 1c) Human Immunodeficiency Virus infection following administration of contaminated Factor VIII concentrate and 2) haemophilia This is exhibited at [WITN3218007]. The registrar insisted that HIV had to be listed on the death certificate, even though we had asked for it not to be included. We felt very strongly about this, as we had been very cautious about telling people S s HIV status.

40. S s death also had to be referred to the Coroner's court. The Coroner's office told us they would not be able to keep the press out of the Coroner's court and I was terrified the press would be there. The inquest was held as the first case of the day on 4 August 2000 and the conclusion was "accidental death". I got the impression the Coroner wanted to do it quickly and quietly, so that it meant that we avoided the press. This was a big relief.

41. We did view S s body at the undertakers shortly after his death but sadly his body deteriorated quickly, and we were then advised that we could not make another visit to view his body before his funeral.

Section 3: Other infections

42. I cannot recall when this was, but we were told by the Royal Free that S had contracted non-A non-B Hepatitis, which is now known as Hepatitis C. It is likely to have been in the late 1980's or early 1990's.

43. S also had liver damage manifesting as cirrhosis of the liver. The doctors did discuss the possibility of a liver transplant with us at one point, but this did not go ahead because of their concerns about the impact of his non-A non-B Hepatitis on a new liver.

Section 4: Consent

44. GRO-B and I do not recall being told of any risks associated with administering Factor VIII in the early days, although I do remember being told that NHS Factor VIII was a safer product than the treatment that were able to access in the GRO-B at that time.

45. As far as I am aware, we were asked for and gave consent to S s treatment and tests; we took the advice of professionals who had much more experience than we did. As I had to give up work in order to care for S I was more frequently involved with the medical appointments, but both GRO-B and our daughter, GRO-B were often involved in hospital visits and appointments spending many hours at various hospitals. In the early days, I carried a pager so that I was on call at all times. I felt we had a good relationship with S s consultants at the James Paget, at the Royal Free and later at Addenbrooke's hospital. S was well liked and we felt that the hospital staff did their best to meet his needs.

Section 5: Impact

Impact on me

46. I was devastated by S s diagnosis. This was not helped by the press surrounding AIDS at the time, particularly as it was referred to as the "gay plague". We believed there was no cure and the media reflection of the disease was horrendous. I was terrified of what would come out next in the newspapers and if there would be a local back-lash if people found out S s diagnosis, despite his young age.

47. I was also in an awful state because I did not know what to tell people. I recall we were advised not to tell people about the HIV infection. I was very careful who I told and what I said to people because of the hysteria about AIDS at the time and people's reactions to the illness. We did tell some trusted people about S s HIV status, which I discuss further below.

48. I kept diaries throughout S s illness but it is now too painful to read them. I cannot look at them, but I have kept them.

Impact on S

49. I remember S as a positive, bright child, full of life and bubbly; he loved sports and games. He wanted to get on with his life and he hated being restricted by his health. He had quite a personality and he coped with the many years of endless diagnosis and infections amazingly well.

50. Over Christmas 1996 I recall that S became lethargic and depressed, and he did feel extremely down at times. But generally, I was amazed at his capacity to bounce back and remain positive after episodes of extreme pain and being exceedingly unwell. Without S s determination to make the best of his situation, I doubt that we would have coped at all.

Impact on S s education

51. S started school in 1987. Prophylactic treatment with Factor VIII was made available to him in 1989 following the splenectomy, when he went onto home treatment. We tried to ensure he went to school as much as possible, but he did have frequent absences.

52. S was often restricted in his school activities because of bleeds; he found this difficult but certainly in his early schooling he was popular with the other students. Either GRO-B or I had to go on his school trips with him, to be able to give Factor VIII if he had a bleed. Sometimes S was limited in what he was able to do because he was using a wheelchair that day. S was an intelligent child and a keen student.

53. Both his first and middle schools were good about his haemophilia. I recall Dr Mitchell went to the schools to talk to them about haemophilia.

54. Although S started high school, he quickly dropped out because of the deterioration in his health. He did have a tutor come to the house for a short period and work was sent home from school but there were many days when he was just not well enough to study.

55. A few years after being diagnosed with HIV, S began undergoing psychological testing at the Royal Free. In 1989 his IQ was 139, which showed he was exceedingly bright. In 1991 his IQ had reduced to 130. In 1992 it was 123 and in 1994 it had reduced to 116, showing that HIV was gradually affecting his brain. It was obvious to us he was struggling.

56. In 1998, S received special dispensation to go to college when he was 15 years old, which made a huge difference because it gave him the chance to make some friends. He had had little chance to socialise during his early teens because his poor health had meant that he had little secondary education.

57. S always enjoyed working on computers. He was very practical, but struggled to write things down on paper. I believe the college allowed S to thrive. He got an identity at college; he became known as "S rather than S and he began to associate with young people again and to socialise. If, however, he was struggling at college due to tiredness, I would go to pick him up at lunchtime.

58. Despite all the illnesses and difficulties he was experiencing, S managed to complete his college course in 2000. He was accepted by the University of GRO-B to study computer science in September 2000. It would have been very difficult for him to go and to succeed as he was struggling more and more to express himself in writing, but he wanted to go to and could have travelled from home.

Impact on GRO-B

59. I believe S s death has devastated us all. It has had such an impact on GRO-B that he no longer wants to build relationships with people. He does not want to become attached to anyone, not even a pet, because the pain of loss is so great.

Impact on GRO-B

60. GRO-B was two years older than S. GRO-B and I both consider that she has been affected the most long-term by S s diagnosis and subsequent death. We used to try to make things as normal as possible for her whilst S was unwell. GRO-B and S were very close to each other and immensely caring and concerned for each other.

61. I could not be at home with GRO-B and at the hospital with S at the same time. As much as I tried to keep life as "normal" as possible for the children, it was very difficult. There were times when we had to drop everything and take S to hospital. This meant GRO-B also had to spend a lot of time at the hospital. She was a loving sister and was often very concerned about him.

62. In summer 2000, GRO-B went tc GRO-B as a GRO-B volunteer. She was very homesick at first, as she was more shy than S and very reserved, but she started slowly to make some friends. She planned to travel around GRO-B with those friends after GRO-B ended. We were thrilled to see her begin to blossom and to grow in confidence. Unfortunately, she was still at GRO-B in GRO-B when S died and we had to get her home from GRO-B It was a difficult conversation to have over the telephone, to tell her that S was dead, particularly since we had forgotten to take into consideration the time difference between GRO-B and UK. S had had a period of better health before he died and we had had no reason to express to GRO-B additional concern about his state of health. The final illness and his death were so sudden; we were all in a state of shock. She had to make the journey back alone, got delayed in GRO-B because of bad weather and I am thankful to this day, that she coped.

63. GRO-B had a place at GRO-B University to study GRO-B in October 2000. She had the option of deferring her place for a year, which would have allowed her to grieve for her brother, but at the time we all thought it was best that she went in the October.

64. Unfortunately, this led to GRO-B

GRO-B

65. I do not know if that GRO-B helped her longer-term; she was so upset afterwards. I do not know whether GRO-B would have been better for her. We feel that GRO-B has never fully recovered following S s death and the traumas she suffered while growing up because of S s deteriorating health. She has GRO-B GRO-B GRO-B This is a lasting and devastating sadness both for her and us. I think S s death has affected her the most; without this trauma in her life, perhaps she could have GRO-B

Impact on family life

66. Looking back, I would not have been able to cope without GRO-B However, I do recall one occasion in around 1995, when S was extremely ill, I was stressed and tired and I thought things would be easier if I had one less person to deal with and look after. Space was also becoming critical. I gave GRO-B the option of moving to a bigger house, or asked him to leave the family home. Fortunately, he agreed we should move to a bigger house and we were able to support each other in our grief after S s death.

Impact on work

67. GRO-B was able to work throughout S s illness, which was fortunate. He did, however, have to stop travelling, and become office based, in 1995. He needed to be closer to home because S was so unwell and I could not be in two places at once; I could not be with both S in hospital and GRO-B at home.

68. I did not work by choice whilst our children were young. I took a return to teaching course in 1988 or 1989 before working in local schools with the English Language Support Service. I took unpaid compassionate leave in 1995 when S was extremely unwell. Initially, I thought this would be a short period of absence, but it lasted three years. In 1998, I resigned as it became obvious to me that I could not go back to work and care for the family.

69. After S s death we set up a charitable trust in S s memory. I did go back to work in 2001 as a part-time teaching assistant and then learning support; I did not feel able to teach as such again. I volunteered to work at the GRO-B and then worked for a company dealing with people/families with housing problems until my retirement in 2017.

Impact on finances

70. I was not concerned with the financial impact of S s diagnosis at the time and I do not consider we struggled financially during his illnesses in the sense that our only concern was coping with the situation we found ourselves in and providing as best we could for our two children. I was reluctant to claim state benefits, however we did complete a Disability Living Allowance application in 1994 with assistance from the Royal Free. The certificate was valid until 3 August 2004.

71. GRO-B was always very careful with money and set aside a contingency fund for anything S might need.

Stigma

72. Initially, we did tell some people about S s HIV status. We only told people we trusted, but even then some people did not want to be associated with us, or be friends with us once they knew. After that, we became very cautious about who we told. Previously, we had been very open and honest people, and it was difficult for us to keep his diagnosis a secret. Even now we do not talk to people about this or mention how S died. Thankfully, there is much more acceptance of diseases such as cancer and it is possible to talk openly about these illnesses, but HIV remains a more difficult subject to talk about.

73. The negativity surrounding AIDS as it was portrayed in the media at that time probably led us to keep quiet about the diagnosis, through fear. We never told GRO-B s parents about S s HIV, but they knew about his haemophilia. AIDS was particularly prevalent in the media whilst S was at pre-school.

74. We recall one incident when S cut his head at pre-school and towels were used to clean the wound. I heard afterwards that the towels were then burnt because of fear of infection. The pre-school never asked us if he was HIV positive but some people obviously did make the association and were scared about it and the risk of possible infection, as they knew he was a haemophiliac. We could not stop people putting two and two together.

75. We both have strong Christian faith but even some churches preached that HIV was *"God's punishment for the gay plague"*. Fortunately, at the time, people did not associate HIV with a child as young as S and perhaps this protected us from his ill-health being associated with HIV. We have always been grateful to those who prayed for S over the years.

Section 6: Treatment, care and support

76. As I have referred to above, we generally had a good relationship with the doctors and consultants at The Royal Free Hospital, James Paget and Addenbrooke's Hospital. On the whole, S received good treatment and the doctors kept us informed. We were always able to discuss S's treatment with them.

77. Initially, when S was first diagnosed with haemophilia, we would take him to the children's ward at the James Paget when we suspected he had a bleed; although S himself was always able to alert us to the fact that he had a bleed. If Dr Mitchell was on duty, S would receive treatment, but if we were seen by a junior doctor, we would often be sent home because there was little external evidence of a bleed. On every occasion, we would then have to go back the next day as the bleeding area would have become swollen and painful.

78. At the beginning, we did not feel able to challenge the diagnosis and we did not know the right questions to ask – we were branded as over-anxious parents or similar. As we became more familiar with S's haemophilia and treatment, we knew to insist that more senior medical staff should be consulted before S was sent home without treatment.

79. I recall that when S's health deteriorated, the James Paget signposted us to GRO-B Hospice, which helped, as the outreach nurse, Jayne, could take S out on his own. This gave him the opportunity to have some time away from us.

80. Once the GRO-B opened in 1992, S would receive his treatment at the James Paget in the centre. In fact, at its official opening, S was honoured GRO-B He became well known by the staff who always made him feel welcome and special.

81. When Addenbrooke's became involved with S's treatment, he was admitted to the adult infectious diseases ward and therefore was in a room

by himself. Either myself or GRO-B would always stay with him in the room. He was always made to feel very welcome on the ward by the staff. We are indebted to Dr Marc Mendelson, then senior registrar in infectious diseases at Addenbrooke's who took such an interest in S and to the staff in the haemophilia centre.

82. Our times in hospital were not always smooth; there were issues and many frustrations on occasions but as we became more confident and staff trusted S s and our concerns, then we were usually able to find a way forward.

Counselling

83. I do not remember either GRO-B or I being offered any counselling although we did attend some family weekends through the Macfarlane Trust. These were helpful as we could talk freely and openly with others but also distressing to hear the harrowing stories of other families. GRO-B did receive some GRO-B
GRO-B

Section 7: Financial assistance

84. We pursued litigation in 1990 regarding contaminated blood with Mark Mildred Napier solicitors. As an outcome of the litigation, we were offered "no fault compensation" and S was awarded £20,000 as a lump sum in 1991. That was held in Court in a trust for S as he was under the age of 18. I cannot recall if we signed anything in order to receive the £20,000.

85. As the Court invested the funds, when S died, there was a £36,000 payment into the estate. We felt guilty at benefitting financially from S s death and so we gave away £24,000 of it, making donations to both the James Paget and to GRO-B at Addenbrooke's and other bequests.

86. Because we were part of the litigation, the Macfarlane Trust contacted us directly regarding financial assistance. The Royal Free assisted us with providing the medical evidence to the Macfarlane Trust.

87. We received payments from the Macfarlane Trust of £70 a month from June 1994. This increased to £120 a month from August 1994. The payments continued until S died.

88. The Macfarlane Trust could make one-off payments and we knew it was always there if we needed it. As I have set out above, GRO-B ensured there were sufficient contingency funds available for S I recall we did make one application for a discretionary payment from the Macfarlane Trust and we received £2,000 for S's first laptop. This meant we could retain the contingency fund for anything else S required. This was the only discretionary payment we applied for.

89. We received a lump sum payment of £20,000 on 15 August 2011 from the Skipton Fund. I understand that this was because S was Hepatitis C positive. We then received a "stage two payment" from the Skipton Fund on 28 October 2011 of £50,000. I understand that this was because S's Hepatitis C had led to liver cirrhosis.

Section 8: Other issues

90. In relation to the litigation, we did not pay any fees to the solicitors. We signed the forms and they proceeded with the litigation. The solicitors applied for S's medical records and the next update we received was that we were offered no fault compensation.

91. Following S's death, using the funds from his estate, we set up the GRO-B ("the Trust") at the end of 2001. It was a charitable trust that provided laptops on free loan to college students, in addition to providing internet access and printers. Initially we wanted to give

his college a computer but they recommended we set up a charitable trust instead and S s tutor became one of the first trustees.

92. We decided to set up the Trust and use some of the money for this purpose because we believe this is what S would have wanted. We recall that a student that went to college with S did not have a computer. S had recently had a new computer and he decided to give his friend his old computer.

93. The Trust closed down a couple of years ago because technology and computers have changed so much and we felt that the Trust had served its purpose. In 2001, when we set up the Trust, the cost of a computer was significant; the first two systems we purchased through the trust were £3,000 each. Over time, the cost of computers has reduced and so the need for free loans has also reduced. I exhibit a copy of one of The Trust's leaflets [WITN3218008].

94. In relation to the Inquiry, my main concern is getting justice for S I want to know whether the authorities knew there was an issue with Factor VIII and whether heat treated products could have been available earlier. S was born in 1983 and I believe he was one of the last people infected. It has had a tremendous impact on our whole family. I have also reflected personally on how this has affected me and my family, and I have written down my thoughts [WITN3218009]. GRO-B life has been blighted by it too. We do not know what S could be doing now, had he not been infected, but he was a bright boy with a great future that was shattered by his health. I hope that lessons can be learned from this failure of the Health Service to provide safe medication.

Statement of Truth

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

Signed ..GRO-B

Dated...30 April 2020...

Statement No: WITN3218001