Witness Name: GRO-B
Statement No.: WITN3119001
Exhibits: WITN3119002 – WITN3119008
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 and I reside at GRO-B I am now retired but I used to work in process and packaging engineering. I initially worked with instrumentation which led to a career in engineering. My final role involved medical processing machinery, which I found more satisfying than a previous position I had involving confectionary packaging machinery. I used to have to travel a lot for work. I retired in 2017 the same year as my wife, GRO-B although GRO-B continued working after me.

2. I got married in GRO-B GRO-B and I had two children; our daughter, GRO-B was born in 1981; and our son, GRO-B: 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 S s medical records and will provide further information to the Inquiry, if necessary, upon completing a review of the records GRO-B has also given a statement to the Inquiry GRO-B

Section 2: How affected

3. We moved to GRO-B in 1980, as I was transferred to the company base there. Both of our children were born in the GRO-B It became apparent quite quickly, around the time S began to crawl, that he had a problem, as he was frequently bruising. We took him to hospital in the GRO-B and he was initially treated with plasma.

Haemophilia

4. S had severe haemophilia A with a clotting factor of less than 1%. It was confirmed in May 1988 that GRO-B was a haemophilia carrier, due to a mutation at her conception. We went to the Royal Free Hospital ("Royal Free") to take part in research. They went through GRO-Bs family and confirmed there is no family history of haemophilia before her.

5. Initially, on 8 December 1983, when we were living in GRO-B we were told S had mild haemophilia A. However, I think this was because they took the blood sample after S had been treated with Factor VIII for 'general bruising'. This is just one reason that I think their knowledge of haemophilia at the time was quite limited. I am not sure if the diagnosis of severe haemophilia A was made in GRO-B or when we visited the Royal Free, in April 1984, whilst on home leave.

Factor VIII Treatment

6. I came back to the UK for my GRO-B funeral in January 1984, and contacted the Royal Free in London. I had called The Haemophilia Society and they had directed us to the Royal Free GRO-B and I consider that this action was pivotal in S s care going forwards. We were then on home leave in the UK in April 1984 and visited the Royal Free with S for consultation. They confirmed the haemophilia diagnosis and spent considerable time advising us of the care S would require. The Royal

Free gave us some NHS Factor VIII blood product to take back to the GRO-B GRO-B with us.

7. We realised we could not get the treatment S needed in GRO-B At that time, GRO-B was still very traditional. Services would shut down in July and August. There were fewer doctors during that period. Their knowledge of haemophilia was very limited, as it was not a very common issue.

8. I worked for an oil company at this time and so I could have easily been sent anywhere in the world to work. We wanted to come back to the UK to obtain treatment for S it was obvious to us that that was the best thing to do. I informed my employer in May 1984 of my need to return to the UK and we moved back to the UK in August 1984.

9. When we returned to the UK, we lived in GRO-B S was treated for his haemophilia at the Royal Free and continued to receive Factor VIII. He also received treatment at GRO-B James Paget University Hospital ("James Paget"). Unfortunately, we believe S was infected through treatment with NHS Factor VIII at the James Paget between August 1984 and early 1985.

10. I recall being given information about how to administer Factor VIII and that we were told to administer it all at once. Veni-punctures on a baby were very difficult and so initially we needed to go to hospital for treatment. I was aware that the Factor VIII had a half-life of 12 hours, which meant we had to mix it and administer it during one treatment. By the second day it becomes, effectively, sterile water; it loses its effectiveness. I recall that when his treatment first began, S required a large volume of plasma to get the required Factor VIII that he needed, however when using the manufactured Factor VIII concentrate, he only needed a small volume.

11. We commenced home treatment with Factor VIII in 1989 and we were taught how to administer the product at home. If, however, S had an additional

problem which we were concerned about, we would still take him to hospital for treatment.

12. The amount of Factor VIII treatment that S needed varied. Sometimes he would go three months without treatment and then need it three times in a week. As an example, in January 1984 he had two incidents requiring Factor VIII; two incidents in May 1984; one incident in June 1984 and three incidents in July 1984.

13. At the end of 1998 GRO-B worked with Dr Mitchell to produce a synopsis of the care S received. I believe some of the focus of this was to consider the many reactions that S had experienced with different medication. I have referred to this within this witness statement, in order to somewhat clarify the dates of his treatment. I exhibit this synopsis as exhibit WITN3119002, and it contains a summary of most of the major infections and illnesses S contracted.

Diagnosis with HIV

14. By February 1985 S was receiving heat treated Factor VIII. By then the problem with contaminated blood seemed to have escalated and heat treated factor was becoming available. I have inferred from this that the authorities were conscious that the UK factor treatment could have been contaminated and the Factor VIII could have been heat treated earlier.

15. In December 1985 we were informed that S was HIV positive. This diagnosis was within 18 months of first receiving Factor VIII. We were not asked to go to an appointment specifically for a HIV test; we had travelled to the Royal Free for a review. We asked the doctor about S s HIV status because of all the media coverage.

16. Then, unexpectedly, we received a letter in the post on 18 December 1985 from Eleanor Goldman [WITN3119003]. The letter stated that S s test

results were with Dr Mitchell. The letter suggested Dr Mitchell would contact us with the results.

17. We called Dr Mitchell, who said he had hoped we would be able to enjoy Christmas with the family and that he wanted to tell us the results after Christmas. We had already guessed the worst from the tone of the letter.

18. We went to the James Paget that day; we just dropped everything and went to see Dr Mitchell. It was suggested to us that S became infected when we returned to the UK in August 1984 or shortly thereafter. We think at some point we were given the batch number of the contaminated Factor VIII which infected S but we were in such a state of shock at the time that I can no longer remember.

19. We generally had a very good relationship with Dr Mitchell. We would always talk through S s health problems with him and it felt like we were all gaining an understanding at the same time. I was aware that another young person in GRO-B had been treated with Factor VIII and had also contracted HIV. We did not tell S and GRO-B about S s diagnosis at the time.

20. The main issue for S from 1985 was the number of infections he contracted as a result of contracting HIV. These became a much bigger issue than having haemophilia.

21. In 1986, S continued to be treated with Factor VIII and also continued to contract a number of infections. He had thrombocytopenia and was given steroids for that. We carried on as "normal", with multiple hospital visits, between 1986 and 1989. He then had a splenectomy at the Royal Free in March 1989. We were told it would help S s platelet levels, as the low levels were compounding the haemophilia problem. As an engineer, I am accustomed to analysing the pros and cons of a course of action, which was what I did when the doctors were considering removing S s spleen.

S's normal "clotting chain" was broken by lack of Factor VIII and now he had low platelets in the blood, which are essentially your "clotting bricks". We understood the spleen was 'destroying S's platelets and we decided the best thing would be to remove his spleen.

22. The doctors had determined that S's HIV had progressed to AIDS in April 1991. I think the virus just took hold over a period of six or seven years.

23. We suspected that AIDS was beginning to affect him mentally. He was always a very bright young boy but that changed over time, which I discuss further below in **section 5**.

24. S was not growing well and he had to receive growth hormones. He had frequent fatigue. By 1991, we were required to monitor S's temperature on a daily basis. There was a varied pattern in those temperatures. He started having an increased number of infections, requiring increased time in hospital at the James Paget or Addenbrooke's Hospital ("Addenbrooke's").

25. S commenced Azidothymidine ("AZT") treatment in May 1991 after we were told the HIV had progressed to AIDS. I cannot recall any visible side-effects from the AZT treatment. We recall that it was all capsules, rather than injections. The AZT was stopped in August 1991 for two weeks due to his decreased haemoglobin and it seemed to be having a negative effect. The purpose of the treatment was to block AIDS progression but there was nothing to stop the damage that had already been done. There was no conversation about what might be or what might happen. All we knew was that it was HIV that had progressed to AIDS, and AZT was the treatment available.

26. As his treatment progressed, the doctors were becoming concerned that S was having more and more infections. From 1991, we dealt with the infections on an incident by incident basis. We dealt with what was happening at the time. I recall he had tuberculosis at one stage. At that time

S was being treated at the James Paget on a day-to-day basis and going to the Royal Free annually or six monthly for his regular reviews.

27. We were beginning to see the impact on S physically. He went from swimming competitively and playing football to not being able to run around. This was due to the physical tiredness caused by the virus. He found his joy in GRO-B which meant that he used his hand eye co-ordination but he was not running around. He stayed with that sport and I took him to several national competitions.

28. The good thing about GRO-B was he did not need to have a certain level of ability in order to compete. You could just go to competitions and pay for your entry. I recall I took him to GRO-B a couple of times to compete. I was pleased that even though he could not do heavier physical activity at that time, he had found something that he could do that he enjoyed.

29. S started immunoglobulin therapy in 1992, which was monthly. We did not tell S and GRO-B about the HIV diagnosis until approximately 1994. At the time we found out about his diagnosis, we thought S was too young to understand it. 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 was still not sure it was the right thing to do at that age; they were still very young. I was not sure there was any point in being that specific about S s illness at that time. However, the Royal Free seemed sure that we should tell them.

30. By 1995, the doctors told us that there was little they could do and that we needed to think about his quality of life. We wanted to keep him comfortable. We just had to manage symptoms and infections as they came GRO-B and I find it really hard looking back as it all melts into one horror story. He just had so many infections and so many admissions to hospital. Certain things would trigger a hospital visit, such as a very high temperature or recurrent high temperatures.

31. On one occasion I recall that Dr Mitchell was not available and the hospital just kept giving him painkillers because he was in terrible pain. They would not give him Factor VIII. I recall he said to GRO-B "*I'm just such a mess.*" GRO-B contacted Addenbrooke's and they said "*what are you doing, you need to bring him here.*" It turned out he had a bleed in his spine, which Addenbrooke's treated with Factor VIII.

32. By 1995 S was at the end stage of AIDS and he became extremely ill. He was so unwell that Dr Mitchell said we should avoid "extreme measures" and concentrate on life quality and troubleshoot problems as they arose. There was no point just continuing to give S the large amount of medications he was taking at that time. S was having frequent antibiotics and high temperatures, but in himself he seemed better without the medication.

33. The doctors then re-started treatment, because he seemed to be coping better, but the infections and fevers came back. I believe that when S seemed to be better without the medication, they decided to gradually increase his medication again, a little at a time, because his body was then more in control. The medications re-started in late 1995.

34. In 1996 S had a liver biopsy. He had multiple blood transfusions and the infections started to increase again. In January 1996 he seemed depressed and lethargic. There were new developments at that time and the medication he was given was not as aggressive. The drugs had been refined so they could work more effectively to benefit S

35. The problem was that the "anti-viral" medication was affecting the rest of his body. He then took additional medication to protect his body and contain what else was happening as an effect of that medication. However, even with the "anti-viral" treatment, he was still "under the hammer" of HIV. The effect of AIDS was that opportunistic infections were able to get in.

36. S developed significant liver problems and frequently looked like he had a "beer belly". 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. They lanced the abscess under anaesthetic, using propofol. S fitted while recovering from the anaesthetic.

37. S had a succession of illnesses and problems throughout 1996 and 1997. In 1996 he contracted pneumonia. It was the case that if an opportunistic infection could be identified then the doctors would treat the specific infection with a specific kind of antibiotic. However, there were some periods where diseases or viruses could not be readily identified. The antibiotics never seemed to completely clear things up for him and he suffered from extreme tiredness [WITN3119004]. In addition, S suffered from a number of allergies [WITN3119005].

38. Despite all of this, S went to the local college of further education in 1998, and he completed his course in summer 2000. We took him to, and collected him from college and he often did his assignment work at home. We intended to take a summer holiday, which we did do, and then in the autumn S would go to the GRO-B however he died before he could do this.

39. GRO-B and I recall the day S died, GRO-B 2000, very clearly. At 11.00pm on the night before, he was sitting in bed having a sandwich. He had been learning to drive and he had driven us to the cinema that evening. He looked very well at the time but by 11.00am the next morning, he was gone.

40. S went to sleep and he woke up in the morning with a raging temperature. This, however, was "normal" for S and so I got up and went to work. GRO-B became concerned at S's condition, so she called for an ambulance. Around this point S actually collapsed. GRO-B told me that the ambulance arrived after a "little while" and took S to the James Paget.

We assume he died on the way. I understand that the team at the James Paget were already waiting for him and tried to resuscitate him. Unfortunately, they were unsuccessful and they decided to stop resuscitation in view of the situation.

41. I was not at the hospital at the time, but GRO-B was. I recall receiving a call from the hospital, although GRO-B believes that it was actually her who called me. In any event, I was at work, and I was asked to go to the James Paget. I went straight to the hospital. I was concerned because GRO-B dealt with all the medical appointments and I was only ever a "reserve". The hospital only called me when GRO-B was unavailable. I assumed S was "just" very unwell. I was shocked to arrive at the James Paget and find out that he had died.

42. S's death certificate, exhibited at WITN3119006, stated the cause of death as 1a) respiratory failure; 1b) pneumonia; 1c) Human Immunodeficiency Virus infection following administration of contaminated Factor VIII concentrate, and 2) haemophilia. The doctors insisted that HIV had to be listed on the death certificate. We asked to not have it included as we had not told people that he had had HIV. We felt strongly about this, but we were overruled by the doctors.

43. S's death also had to be referred to the Coroner's court. Before this, I had not considered that there would have to be an inquest. The Coroner's office told us they would not be able to keep the press out of the Coroner's court. There was no post-mortem report, although they would have completed one if we had felt strongly about it. At that stage we could not have coped with S undergoing a post-mortem.

44. I believe somebody at the James Paget made a phone call to the Coroner's court and suggested that they held S's inquest as the first case of the day. The inquest was held on 4 August 2000 and the conclusion was

"accidental death". I got the impression they wanted to do it quickly and quietly, to avoid the press being present. We were very grateful for this.

45. Following this, there were some difficulties at the undertakers because of the risk of infection to their staff. When we first viewed S s body we were told that we should not attempt to view S s body just before the funeral, as his body had deteriorated quite quickly, and this deterioration would obviously continue. They said it was not advisable for us to go back and view the body again.

Section 3: Other infections

46. We were told S had contracted non-A non-B Hepatitis, which later became known as Hepatitis C, but I cannot recall when exactly we were told about this. We were given the diagnosis by the Royal Free and we knew about it for a long time. It would probably have been in the late 1980's that we were first informed.

47. S also had liver damage and cirrhosis of the liver. The doctors discussed a liver transplant with us at one point, but they told us they were concerned about doing this in view of the haemophilia.

Section 4: Consent

48. I do not recall being told of any risks associated with administering UK Factor VIII concentrate.

49. As far as GRO-B and I recall, all of S s treatments and tests were conducted with our consent. We felt we had a good relationship with S s Consultants and we could ring them if we had any problems. We were really fortunate we were able to discuss the treatment with the doctors. A significant number of those medical professionals attended S s funeral. This shows the care we believed we had from the people on the front line. I feel they were dealing with the aftermath of a government-led decision.

Section 5: Impact

Impact on S

50. S was always a positive child and he coped with the Factor VIII treatment well because he wanted the bleeding to stop so that he could get on with life, like all children do. He had quite a personality; he was bouncy and full of life. S did not want to be restricted.

51. S coped with the diagnoses and the recurrent infections amazingly. Sometimes he was very depressed, although he generally had such a positive outlook. His personality and spirit were quite amazing. He had periods when he was really poorly and in pain and he got depressed but he did always bounce back.

Impact on S's education

52. S started school in 1988 and due to the haemophilia he missed quite a lot of his schooling. Prophylactic treatment with Factor VIII was not easily available to S until 1989, when he went onto home treatment.

53. S had restricted school activities and GRO-B or I had to go on school trips with him. Sometimes S was limited in what he could do because he was using a wheelchair. This did not limit his personality though. I recall one day we were called into school because staff were worried that he was doing wheelies in the playground; that was the type of child he was.

54. The first school he went to was quite good about his haemophilia, and his middle school were very good too. Dr Mitchell insisted on visiting his middle school to explain the situation to staff. By 1996, S was rarely at school. Unfortunately, S attended little secondary school as the illnesses were so frequent. He was only there the odd day.

55. Also at this time, around early 1996, we requested home tutoring for S basically at the beginning of secondary school.

56. It was clear to us that the HIV was affecting S s brain and he received 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. It was obvious to us how much more he was struggling at school and that he was not well enough to study. It was evident from the psychological testing that the HIV was affecting his brain. This can be evidenced by the exhibited examination report prepared by the Royal Free in 1994 [WITN3119007]

57. S received special dispensation to go to college when he was 15 years old, in 1998, and that made a huge difference because he made some "normal" friends. There was a big mix of people of all ages and he had a varied group of friends. He also began taking growth hormone, although we cannot recall when. That made a huge difference; he was small but he did start to grow.

58. From a practical point of view, S was very good with computers but he struggled to write things down on paper. He would often dictate his assignment and then we would type his dictation up for submission at college.

59. In some ways the college allowed S to thrive. It gave him an identity and he loved computing. He was at college three days a week. If he was tired, we took him out of college at lunchtime. College was a noisy place and often he needed the quiet.

60. From 1998 to 2000 S managed to complete his college course. He was accepted by the GRO-B to study computer science in September 2000. It would have been very difficult for him to go, but he

passed his college course and he believed he was going to University that autumn.

Impact on me

61. The impact on me of losing S was one of total devastation. My emotions have ranged from immense sadness through to extreme anger at having to basically stand on the side-lines and watch the progressive, gradual, creeping destruction of a promising young life. I saw an intelligent and compassionate young person just "eaten" away.

62. GRO-B thinks that S 's death affected me more than it affected her. She thinks this because I do not want to build relationships with people now. She rightly believes I do not want to become attached to someone to then lose them; not even a pet.

63. Pondering on this, I think that perhaps, because I am an only child, I never did need to rely upon building relationships with other people. I liked to work on my own and with machines rather than people.

Impact on GRO-B

64. GRO-B was two years older than S and we consider that, long-term, she has been affected the most by S 's diagnosis and subsequent death.

65. GRO-B spent lots of time at the hospital with S They had a very good relationship. She was a very loving sister and often very concerned. GRO-B was always much shyer and more nervous than he was. We used to try to make things as normal as possible for her whilst S was unwell.

66. Unfortunately, GRO-B was away when S died. She was at GRO-B GRO-B and I remember her being very homesick at first, but then she started to blossom. She had made some friends and was planning to travel around GRO-B with those friends. We had to call and tell her on the phone that her brother had died. This was very difficult with the

time difference and she was upset that we did not let her know that he was ill. We explained to her that at 11:00pm the night before he died, he was fine. She made the journey back, but I seem to recall she got stuck in GRO-B 'overnight' on her own.

67. GRO-B had a place at GRO-B University to study GRO-B in October 2000. At the time we thought it was best that she went, rather than deferred her place, but in hindsight perhaps she should have taken a year out then.

68. GRO-B GRO-B S's death knocked all of the confidence out of her. Of course, taking this GRO-B made returning to her studies difficult, as her friends had already graduated. She was no longer in the same year as anybody she knew. However, GRO-B GRO-B GRO-B did return to the university to complete her degree.

69. I do not know if that GRO-B helped her longer-term. She would have her GRO-B GRO-B Of all of us, I think her brother's death has affected her the most.

Impact on family life

70. S's illness affected my relationship with GRO-B In 1995 we moved into a bigger house because 'space' became very critical for us. To my recollection, I was given the option of either leaving the family home altogether or moving to a bigger house. GRO-B told me that she could not cope with all of the issues that she was going through at the time and she thought that it would be easier if she had one person less to cope with. I said *"let's not split up, let's move somewhere bigger"*.

71. Fortunately, there has been no impact on our relationship with GRO-B and it was not strained. GRO-B has told us that it was only after S died, when

people said to her *"that must have been very difficult"*, that she really appreciated what we had been through. At the time she did not think about it.

Impact on work

72. I worked throughout S s illness. I was always travelling for work but in 1995 I had the opportunity to become office-based for the first time in over 20 years. I took the opportunity to be at home as S was so unwell. I had to go on one or two trips abroad but I was always able to get home when I needed to. I stayed at that company until 2003.

73. I was made redundant in 2003, which was not a surprise, and it was not related to my personal situation at the time. I spent the summer of 2003 applying for jobs. My mother was still alive but she was not well and so I spent more time with her.

74. I started a new job in September 2003 and my mother sadly died in GRO-B 2003. I remained at that same company until I retired in 2017.

75. My employers were generally very good to me and I recall at one point I called them from hospital because S was very ill, and they said not to worry at all. I do not know if I told them about S s HIV status, but they knew he was often ill and that it was not going 'well'.

Impact on finances

76. At the time all we were thinking about was coping, and we were not thinking about financial impact. Generally, we were very reluctant to claim benefits, although we did complete a Disability Living Allowance application in 1994 with assistance from the Royal Free. The certificate was valid until 3 August 2004.

77. By the time we moved to GRO-B in 1980 we were buying our first house. I was always very careful with money and ensured that I had some money kept

aside for S a contingency fund. There was always money there if something broke or if he needed something.

78. "We were not millionaires" but living in GRO-B we were relatively comfortable. We were not struggling financially when we were dealing with S's illnesses, but in the early days we had to be very careful. In the mid 1980's I was self-employed for a while, and one month I had to choose between car tax or TV licence, to keep to my self-imposed budget.

Stigma

79. We did tell some trusted people about S's HIV status. Some people did not want to know us any more after we told them and that made us very cautious about who we then told. We did lose some friends when S was diagnosed with HIV. Previously we had been very open and honest and it was difficult for us to then keep his diagnosis a 'secret' and not talk about it.

80. I feel the media presentation of HIV and AIDS at the time probably led us to keep quiet. Initially there was a fear surrounding AIDS, particularly in the local press. I also never told my parents about their grandson's HIV status, although they knew he had haemophilia. In 1985, when HIV was in the press, I do not think they understood HIV. They were already struggling to understand S's haemophilia.

81. We have strong Christian faith but at some churches we were hearing the comment that HIV was "God's punishment for the gay plague". We were concerned that people at church might find out about S's HIV status.

82. When S was in pre-school, there was still quite a lot in the press and media about AIDS. The pre-school never asked us if he was HIV positive. None of the schools S attended knew that he was HIV positive. However, they knew that he was a haemophiliac and you cannot stop people putting two and two together.

83. We did not tell S and GRO-B about S s HIV status whilst they were younger. This was a good choice, as we heard other patients talking in hospital about those that had contracted HIV as *"dirty buggers"*. At the time, people did not associate HIV with younger people so they did not suspect S s diagnosis.

84. Even now we tend to not freely talk to people or mention how we lost S There are two reasons for this. The first is that death is generally embarrassing for some people. And the second reason is that people may ask questions and we would not know how to answer them. Initially we were terrified someone would find out that he had died of AIDS.

Section 6: Treatment, care and support

85. Generally, we had a very good relationship with the hospitals that we attended; James Paget, Addenbrooke's and the Royal Free. However, when additional problems arose it was usually when he was seen by staff who did not know him or the extent of his medical issues.

86. We consider S had good treatment and we were kept informed of his progress. We were fortunate that we had doctors that we were able to talk to. We were put in touch with a children's hospice and an outreach nurse who used to go out with S This gave him some time away from us as well. Even on school trips he always had to have a parent with him, so he did not spend much time without one of us.

87. At the James Paget S was treated at the GRO-B centre and at Addenbrooke's, S was always admitted to the infectious diseases ward. It was a mixed blessing; he was a child on an adult ward and that made him special to the nurses, but it did mean that he was separated from other children as he was not on a children's ward. Nevertheless, he became so well-known at the hospitals, he was always welcomed and well looked after.

Counselling

88. I do not recall that GRO-B or I were ever specifically offered any counselling, however I would say that I always felt that I could have called the Royal Free and asked them for counselling, because of the good relationship we had.

89. When we talked to the doctors we were always talking about S not about us GRO-B

GRO-B

Section 7: Financial assistance

90. We pursued litigation in 1990 regarding "contaminated blood" with Mark Mildred of 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. We cannot recall if we signed anything in order to receive the £20,000.

91. When S died there was a £36,000 payment into his estate from the Court as the lump sum payment had accrued interest. We could not cope with it at the time and we felt a sense of guilt at benefiting financially from S s death. In the end we gave away some £21,000 of it.

92. Because we were part of the litigation, we were in contact with the Macfarlane Trust directly, regarding financial assistance. I recall the name of the person that we had most contact with as Ann Hithersay.

93. We received payments from the Macfarlane Trust of £70 a month from June 1994. This increased to £120 a month from August 1994. The Royal Free completed some paperwork for us. We continued to receive the Macfarlane

Trust monthly payments during S s lifetime. The Macfarlane Trust could make one-off payments and we knew the money was always there if we needed it.

94. We did request support through the court held funds in 1996 and received £2,000 for S s first laptop. We applied for this because we wanted to keep our contingency fund available for him, in the event he needed anything very quickly, but felt the laptop would help him with his studies.

95. We did not apply for any discretionary payments from the Macfarlane Trust because we did not need anything. We were really reluctant to claim anything as we felt S was our responsibility.

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

97. This whole Skipton Fund thing seemed somewhat silly to me - what with these payments being made over 11 years after we had lost S

Section 8: Other issues

98. 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 we did not have to go anywhere or do anything more. The next thing we were told was that we had been offered 'no fault' compensation.

99. Initially we were not sure whether to take part in the litigation and so we spoke to the Royal Free. They said if it turns out to be beneficial and we were

not involved, and if S was still alive then we might regret a lost opportunity. They said it could not do any harm but could potentially help.

100. Following S s death, initially using funds from his estate, we set up a charitable trust GRO-B The trust was called the S GRO-B ("the Trust"). The Trust provided laptops on free loan to college students. We also paid for and provided internet access to students through dial-up, and printers. It went live at the end of 2001.

101. We decided to set up the Trust and use the money for this purpose because we believe that this is what S would have wanted. I recall that a student that went to college with S had not got a computer S had recently had a new computer and he wanted to give his friend the old computer. Initially we wanted to give the college two computers but they recommended we set up a charitable trust instead. S s tutor was one of the first trustees.

102. The Trust closed down a couple of years ago because technology and computers have changed so much since 2001. When we set up the Trust, the cost of a computer was significant; the first two systems we purchased through the trust were about £2,000 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 [WITN3119008].

103. In relation to the Inquiry I hope that, at least for a generation, people in authority are more careful with making cost-motivated decisions. I suspect that in two or three generations time, the knowledge of the impact of these decisions will have been eroded.

Statement of Truth

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

Signed: ……GRO-B…………

Dated: ……30 APRIL 2020……

STATEMENT NO: WITN3119001