**Witness Name:** GRO-B
**Statement No**: WITN4730001
**Exhibits:** WITN4730002 - WITN4730014
**Dated**: 21 July 2021

# INFECTED BLOOD INQUIRY

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## WRITTEN STATEMENT OF GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 October 2020.

I GRO-B will say as follows: -

## Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1959. I reside at GRO-B I married my wife GRO-B in 1987, and we have three children, and four grandchildren. In 1980 our eldest son GRO-B was born. Then, our youngest son GRO-B: S was born on GRO-B 1984 at GRO-B GRO-B Our daughter GRO-B was born in 1985.

2. I am currently employed as a Senior Field Technician (Water Utilities) at the GRO-B Before this, I had worked within the Water Network in Scotland for over 40 years. I have worked as a manual worker for the whole of my life.

3. I am making this statement jointly with my wife GRO-B we intend to speak about our son S infection with Hepatitis C ("HCV") and his subsequent and recent death on GRO-B 2020, after having received a contaminated blood transfusion between 1984 and 1989.

4. In particular, the nature of how we had learnt about his infection, how his illness had affected S and our family thereafter, and the financial assistance we have received. S date of birth is GRO-B 1984.

5. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. NOT RELEVANT NOT RELEVANT

6. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

7. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates. This is particularly in relation to the dates surrounding the earlier years of S life.

8. I have provided this witness statement with help from my wife GRO-B We have constructed this statement with access to some of S medical records. However, upon inspecting his medical records, my wife and I had become aware that the records relating to the first four years of his life are missing. Such records relate to the treatment he had received within the first four years of his life, and the respective blood transfusions received.

## Section 2. How Affected

9. In 1980, I met my wife GRO-B She is the best thing that has ever happened to me, and she is the love of my life. I love her more as each day passes. Between 1980 and 1985 we had our sons GRO-B and S and our daughter GRO-B

10. S was born on GRO-B 1984, at GRO-B Immediately after his birth, S was examined by the medical staff, it was apparent that there were complications with regards to S health. He was immediately transferred by ambulance to GRO-B GRO-B where we referred to the care of a GRO-B

11. At the face to face consultation with GRO-B we were told that there was something wrong with S After a number of tests had taken place, he was diagnosed as having Anorectal agenesis, which is an extremely rare type of anorectal malformations ("ARM") characterized by the absence of the anus and abnormal connection of the rectum. We were told that he had a missing left kidney, a deformed right kidney, part of his bowel was missing, his bladder was deformed, and his bladder was not connected to his back-passage.

12. S diagnosis is confirmed in a document contained within his medical records dated, 23 August 1988 (exhibited below at **WITN4730002**), which states the following:

> *"Diagnosis:*
>
> 1. *Chronic renal failure secondary to fused ectopia and obstruction left dysplastic kidney and absent right kidney.*
> 2. *Anorectal agenesis with sigmoid colostomy."*

13. S was rushed to surgery that same day on GRO-B 1984, so that he could undergo an operation to have his front passage connected, and undergo an emergency colostomy. Poor renal function and abnormal renal tract was discovered following his colostomy for anorectal agenesis.

14. Thereafter, when S came out of the surgery, we were taken to a ward whereby he would reside so that the medical profession could observe his health. However, five weeks after the surgery, we were discharged home. They said that there was nothing else they could do for S and we should take him home.

15. S was only five and a half pounds at the time, and the medical professionals in charge of his care were not hopeful that he would survive much longer due to the deterioration in his health. However, by a grace of god, S had survived the weekend, and we took him back to GRO-B on the Monday after his weekend home.

16. When we entered GRO-B the doctors who had previously been in charge of his care were shocked that S had survived the weekend. They had told us something along the lines of "*he has survived?*" Thereafter, the doctors did all they could, as they wanted to give him a chance at life. He was kept in a ward for a period of around another two weeks, whereby he was given treatment of various types, medication and tests. Looking back it appeared that the hospital were limited as to what they could do for him.

17. On 26 June 1984 S was given a blood transfusion as treatment. I made a handwritten note of this. We think this was because he was anaemic.

18. GRO-B and I were taught how to provide medical assistance to S for when we would return home. This included how to feed him and care for him. We were told how to manage his double barrel colostomy.

19. In July 1985, when S was aged around one years old, we had noticed that he was extremely ill with regards to his health. We decided to seek medical assistance from our General Practitioner ("GP") GRO-B We were

referred to GRO-B straight away for a face to face consultation with GRO-B GRO-B

20. After initial observations GRO-B had told us that S was suffering with acute chronic kidney failure. He wanted S to undergo an operation that day as he did not believe that S would survive much longer, but after doing some research, he was advised to place S on a Continuous Ambulatory Peritoneal Dialysis ("CAPD").

21. A CAPD was a procedure whereby it replaces the kidney's regular function of filtering and removing waste products and excess fluid from the blood. During peritoneal dialysis, between one to three litres of fluid is put into the space through a catheter attached to your abdomen. The dialysate then sits there for several hours whilst waste products pass from the capillaries into the liquid. It is then drained out into an empty bag and thrown away.

22. Thereafter, S would undergo a CAPD every six hours of his whole life, of which, the process lasted one or two hours. The next day, we had noticed that he was figuratively up on his feet, and his health had enhanced.

23. After about six weeks S was discharged home. We were also given a CAPD machine, which we were taught how to use by the medical staff at Yorkhill whilst S resided at the GRO-B I use the word discharged very loosely as S was in and out of the hospital.

24. Within six months or so, we attended a face to face consultation with GRO-B GRO-B at GRO-B whereby we were told that he wanted to investigate S bowel.

25. Thereafter, within week or so, S had undergone surgery where they had made an incision from his scrotum right up his back to try and find S bowel. At that point, they could not locate his bowel GRO-B wanted the surgeon GRO-B to investigate further, however GRO-B refused, as it would have endangered S life.

26. Thereafter, S was placed on the kidney transplant list. There was some conversation with Great Ormond Street and GRO-B regarding the transplant. Great Ormond Street did not want S to have the kidney transplant GRO-B persuaded them otherwise.

27. From July 1985 until August 1987, S received regular dialysis treatment. At one point, GRO-B and I can recall seeing S running around and he caught his dialysis tube and it started to leak everywhere. We took him to GRO-B so that his line could be replaced.

28. Thereafter S had multiple lines put in within over the course of the next month. Each line was meant to last him a couple of months, however, with S his lines kept clogging up which meant the dialysis did not work properly. At one point, we would go to the hospital every day to get his line changed.

29. S was having a hard time consuming food. We fed him for ten hours a day through a nasogastric feeding tube, and one day a week, we would take him off of the nasogastric feeding tube to encourage him to eat solid food.

30. In January 1987, S became very ill, so on 28 January 1987, we had attended a face to face consultation with GRO-B at GRO-B when we were told that S had to have a CAPD fitted permanently. He had asked us for our consent, but he had also stated that if we did not give consent, he would still go ahead with the procedure as it was necessary to save his life as he was so ill, S was about to die.

31. A CAPD was fitted permanently to S there and then, right in front of our eyes. We held S on our laps whilst the medical staff conducted the procedure. As parents we fully grasped the severity of his medical needs.

32. On Friday 21 August 1987 S had undergone a cadaveric renal transplant (kidney transplant) at GRO-B when he was aged four years old. After eleven hours had passed, we were told that the transplant had not gone as planned. The medical staff placed him on a life support machine thereafter, as he was not in a good state with regards to his health.

33. On Saturday 22 August 1987, S had undergone another operation to correct the operation that had taken place on Friday 21 August 1987, but, this also did not work.

34. On Monday 24 August 1987 S had undergone surgery to have the kidney removed, after the surgeons had realised that the kidney transplant was not saveable, he did not have any kidneys.

35. S was placed back on the kidney transplant list thereafter, and had to undergo regular haemodialysis on a temporary basis. This is a process whereby his blood would be purified in the absence of not having a kidney. As S circulatory system was not very strong, the only place that they could get a line into his body, was through the femoral artery of the groin. This process was undertaken three times a week.

36. On 16 June 1987, fathers day, GRO-B and I were telephoned at home by GRO-B who had told us that they had a kidney for S and that they wanted to undergo a kidney transplant immediately. We were told that the procedure was that the medical staff at GRO-B would take him in and do tests to see if the kidney was a match to S If a match was found, then the procedure would go ahead.

37. In readiness, we got the kids ready to go to GRO-B mother's house. We received a telephone from one of the doctors at GRO-B who told us that the procedure was to go ahead as planned.

38. On 16 June 1987 S underwent another kidney transplant.

39. Once S had come out of theatre, the surgeon told us that the kidney S had received was the wrong blood group, but as the condition of the kidney was too good, they did not want to pass up the opportunity to give it to S He was given anti-rejection medication as a result of the kidney transplant. We were soon told that the kidney transplant had been a great success. After testing had taken place, the kidney was found to have a function rate of 85% which was good news.

40. Within a document contained in S medical records, dated 23 August 1988 (exhibited below at **WITN4730002**), it states the following:

> *"Nutrition:*
> *Very reluctant to take oral feeding. Required encouragement with solids and still requires nasogastric supplementation. Chronically very poor eater. Requires nasogastric feed 6 nights a week of 150 gm ducal and 25 mg Neocate. Only recently beginning to take solid food spontaneously. Has been very reluctant to chew and swallow."*

41. Before the final transplant in1989, we attended GRO-B so that S could undergo surgery for another dialysis line to be inserted thro his neck and chest. After taking him into the operating theatre and handing over S to the surgeons I can recall trying to get out of the theatre, but I could not remember the door to use. I turned around to ask which way was out and saw S on the operating table where his chest open. They had worked so quickly. We had not long admitted S to hospital, and within minutes, they had opened up his chest so that they could operate on him.

42. After a number of hours GRO-B and I were getting worried, as we had not heard any news and we had not seen that S had come out of the theatre room. We asked Nurse GRO-B who was on duty at the time whether she had heard any news, to which she had not. However, just as she told us this information, a male doctor who was of Chinese origin came on to the ward to ask Nurse GRO-B whether they had any beds free; pointing at the bed that S was due to return to. Nurse GRO-B had replied stating that they did not have any beds free, and that S was due to return from theatre shortly.

43. In response, the doctor had said something along the lines of "*why are they trying to save that baby, he is dying?*" Nurse GRO-B looked at him with confusion, as that this was the first time she had heard any news with regards to the state S At the time I was close to where this conversation was taken place and I heard what was being said. I do not think that the doctor

knew that I was close by, or, that I could hear what he was saying. I was so shocked.

44. Nurse GRO-B immediately ran down to the surgery room to find out what was going on, as I was worried. Later that evening at about 11pm GRO-B came to see us, he was one of the consultants under GRO-B who had been in charge of S operation. He was covered in blood, to which we immediately knew that it was S blood.

45. GRO-B had told us that during the operation, the main artery in S heart had burst open, and that they were fighting to save his life. Also, that they did not know if, due to the blood lost, he would have brain damage or any damage at all. He then told us that S had been taken down to the Intensive Care Unit at GRO-B We went down to see S straight away.

46. The next day, to our relief, we noticed that S brain had not been damaged as a result of the medical complications. He was sitting up and talking to us. Within the next few days, he was able to walk around. His powers of recovery were amazing.

47. Thereafter, S resided at GRO-B for two to three weeks. He had undergone a number of treatments, including regular dialysis, and a number of blood transfusions. I can recall seeing units of blood hanging up on stands in the hospital next to S bed throughout his stay. I do not know as fact, how many units of blood S received during his blood transfusions throughout his stay at GRO-B

48. Neither GRO-B or I had consented to S receiving the blood transfusions in 1988/1989, and we definitely did not sign for anything. However, at that time, we did not question the authority of the medical profession. We were both young parents at this point in time. The Renal Unit at GRO-B was really great, and we spent so much time up there. Our children were brought up with the doctors, we did not question anything.

49. Thereafter, as GRO-B and I worked alternative work patterns; where I worked in the day and GRO-B worked in the night, one of us was always able to be with S at GRO-B

50. On one occasion, in 1989, I got to GRO-B at around nine o'clock at night; after finishing work so that I could get S off to sleep and so that GRO-B could go to work. However, upon reaching the ward where S resided, I had seen that the staff nurse who was in charge of his care was taking S off his dialysis.

51. After signing off the drugs, the staff nurse had drawn the saline solution in readiness. However, as she drew the saline solution, half the syringe ran past the line. I looked at her, and she had stated that this would be safe enough; if I call for the sister I would be in trouble as she had already signed the drugs off for that ward. She continued to flush out his lines. I did not think anything of this at the time as I had been reassured that everything was okay with regards to his safety.

52. The next day we took S and the rest of the family off to the local Gala, which was a Fayre in our town which had a range of activities, games, and entertainment.

53. However, upon getting home that night, GRO-B went to pick S up to lift him onto the potty. Upon doing this S fell to the side of his potty. She thought that this was strange as his legs were buckling and he went floppy, but thought maybe that he was just tired after an eventful day at the Fayre. GRO-B put him to bed as normal.

54. The next day, we woke S up as normal, he was fine. He was due dialysis and we took him up to the hospital. When GRO-B arrived at the hospital she informed the staff what had happened the night before and was met with the response, "*Do not to worry* GRO-B *your mind works overtime, you know what you are like.*" Upon hearing this, we were relieved. S was then prepared for his dialysis.

55. Upon drawing the line, blood only came out of the one line; it should have come out of both. The nurse stopped and then tried again, she tried to draw the line back and it was blocked. At that point she should have stopped but she carried on and pushed whatever the blockage was into S system. S suffered a massive stroke as a result. GRO-B had noticed that S eyes starting to flicker and she sent for a doctor to attend to him immediately. The doctor on the ward at the time then sent for a Neurologist.

56. Retrospectively we were told that the incident on the potty had been a Transient Ischaemic Attack ("TIA"), which is a condition where the blood supply to the brain is temporarily disrupted. It has not ever been confirmed what the cause of S TIA was, bu GRO-B and I believe that it was as a result of the dialysis which had previously gone wrong before the incident I have just spoken about.

57. Thereafter, S suffered with paralysis down the right side of his body. He was unable to speak for around six months his movement was very restricted. In the end S never made a full recovery. Whilst he did gain a restricted amount of movement back, he was wheelchair bound from there on for the rest of his life.

58. In 1989/1990, at the age of five years old, S suffered an epileptic fit. At one point, he suffered on average thirty seizures a day. The doctors had tried every combination of medication they could, and nothing had worked to curtail his seizures. We have retrospectively found out that seizures can be caused by strokes, of which S had undergone a year previously. We were constantly worried about S seizures as he would be forever falling to the ground and hitting something on the way down.

59. S was covered in bruises as a result of these seizures, I remember on one occasion GRO-B had to rush S to the Accident and Emergency Department ("A & E") at New Stobhill Hospital ("Stobhill"),133 Balornock Rd, Glasgow, G21 3UW. S colostomy was blocked.

60. GRO-B and S were seen by one of the doctors at A & E; she noticed that S had not seen this doctor before. After GRO-B had told the doctor the symptoms S had been experiencing, he asked whether she could take off S shirt so that he could examine his chest.

61. Upon lifting up S top, all of his bruises appeared all over his body which he had been sustained as a result of his constant knocks and grazes during his seizures. He was covered in surgical scars as well. The doctor immediately looked up and said something along the lines of "*where did those bruises come from?*" GRO-B went to answer him, and the doctor said, "*I am speaking to* S *where did those bruises come from?*" S replied stating "*I do not know where my bruises came from, you need to ask my mum.*"

62. If ever there was a red flag with regards to signs of the medical profession getting the Social Services involved for fear of something sinister going on within the family home, this was it. S reply was a massive red flag. In that moment GRO-B thought that the doctor was going to get Social Services involved.

63. I can fully understand that the medical profession have a duty of care to their patients, but as a mum GRO-B felt that this is one of the worst accusations. Luckily, after returning from consulting with one of the other doctors at GRO-B no further action was taken.

64. When GRO-B took S back to the car she immediately asked S in an enraged state something along the lines of "*what do you mean saying to the doctor 'I do not know where my bruises came from?' What do you mean?*" S said 'I don't know, I couldn't remember'

65. Thereafter, until 2017 S attended primary school, secondary school and College. Throughout this period, GRO-B and I had noticed that he was always so held back. It was not the kidney that was holding him back as that was functioning well above average. All the other children who had undergone

kidney transplants were up and doing things; except for S We could not understand why?

66. We noticed that S was experiencing one illness after the other. He was always tired, lethargic, fatigued and cold in temperature. His face would still be drooped on the right side of his face as a result of his stroke, and he remained reliant on his wheelchair. He was put on antibiotics for the rest of his life.

67. From the point of S second kidney transplant on 16 June 1987 and 2017 S had three follow up's with regards to his kidney function. The first appointment was on 03 March 2004, the second appointment was on 25 August 2010 and the second appointment was on 02 August 2016.

68. Within a letter dated 06 June 2017, from GRO-B Renal Transplant Clinic, University Hospital Monkland's ("Monkland's"), Monkscourt Avenue, Airdrie, ML6 0JS, to GRO-B entitled GRO-B – Renal Transplant Clinic – Tuesday 6 June 1017," (Exhibited below at **WITN4730003**), it states the following:

> *"This is to confirm that S aged 33, is a regular follow-up patient at the Monkland's Transplant Clinic S was born with a number of congenital conditions. These included renal agenesis for which he received a transplant at a very early age. His transplant function has been more or less stable over the years, although more recently, his readings have been more turbulent and required closer monitoring. Another congenital defect that indirectly affects S transplant is anorectal agenesis. For this S has a bowel stoma which at time is over active and makes S dehydrated which causes turbulence in his transplant function."*

69. In July 2018, we had noticed that S health had deteriorated. We sought medical assistance from Monkland's, and we were told that we needed to bring S to Monkland's as soon as possible.

70. After initial observations had undergone, S had had a number of blood tests in an attempt to determine the cause of his ill-health. When the results had returned, it had shown that nothing was out of the ordinary. We were discharged home the same day.

71. In August 2018, S became very ill again, so we determined that there must be something wrong. Similar to that of July 2018, we were told to bring S to Monkland's, where he had undergone a number of blood tests. Similarly, when the test results had returned, it had shown that everything was fine. Again we were discharged home.

72. However, at the beginning of September 2018, for the third time, S health had deteriorated. His foot had swollen, and he was constantly scratching all over his body to the point that he would bleed. When he started to bleed, it took ages to stop his bleeding. S would also bruise easily. He would itch his eye and would get two black eyes. He would suffer a knock, and he would get a bruise.

73. At the beginning of September 2018, we arranged a face to face consultation with GRO-B at Monkland's. Upon attending the face to face consultation, we asked whether there anything wrong with regards to S liver. Upon hearing this, the doctor took off S glasses and took a closer look. The doctor said have you noticed that his eyes were slightly yellow? To which we were astounded that we had not noticed this before of S

74. Thereafter, the doctor had said that they were going to do some tests, and sent off for scans.

75. In October 2018, we were told that the results had returned and that it had shown that his spleen had enlarged. Also, that they thought it was may be rapid liver cancer. The doctor then carried out further tests.

76. On 16 October 2018, we attended Monkland's for a further face to face consultation with GRO-B asked the doctor how S liver was, to which he replied stating that his liver was absolutely awful, and that he was

jaundiced. In response, I had notified the doctor that S was still scratching all over his body and that he was bleeding as a result.

77. At that point, a further blood test was taken. We were not told in advance as to the types of tests, no specifics were mentioned.

78. On 20 October 2018 we received a telephone call from GRO-B at Monkland's. He told us something along the lines of "*I am very sorry, but* S *has tested positive for HCV.*" GRO-B view was that we had now found out what was wrong with him, we didn't have a clue as to what this would mean long term GRO-B said they were to admit S to the Infections disease ward under Dr Kennedy. S was admitted that day.

79. From the point at which S had been diagnosed with HCV, we had not been provided with any information or leaflets about what HCV was as an infection. We were also not told any information surrounding what his infection meant for him thereafter, or about the full extent it would have on his and our lives. We were never told what the potential consequences of his HCV meant fo S

80. GRO-B had sourced all our knowledge surrounding S HCV from research on Google. GRO-B would print off sheets after sheets of information. GRO-B and I wanted someone to tell us what HCV was as an infection, how to manage it, and how to be safe. In the end, I knew so much information that we were highlighting things to the doctors. Thereafter, we do not consider that we had been given full and adequate information to have allowed us to understand and manage his infection. We were also not told any information about the risks of others being infected as a result o S HCV infection.

81. Whilst I do consider that GRO-B and I would have preferred to have been notified of S HCV infection at a face to face consultation, we would have rather have been told at an earlier point in time over the phone, than in person at a later stage.

82. Thereafter, it was down to GRO-B and I to tell S about his HCV diagnosis, as was usual S just took this in his stride. He always felt that we would take care of him and this was just another thing. I do not think he understood the gravity of the diagnosis.

83. GRO-B and I do consider that there was ample opportunity prior to 2018 for the medical professionals in charge of S care to have provided a diagnosis at an earlier point in time.

84. Subsequent to S HCV diagnosis in October 2018, in 2015 S fell and hit his leg. His leg turned black straight away with bruising. The nurses in charge of his care at home gave him painkillers and he had undergone dialysis. Thereafter, his health had taken a turn for the worst.

85. S was taken to Monklands Hospital at 23:00 hours by ambulance. As soon as he was admitted, S had blood taken and he was placed into a diabetic coma. They had ample opportunity to test for the presence of blood borne infection, to my knowledge, but this did not take place.

86. After a period of one day, S was taken out of his coma and was discharged home after a week.

87. I also consider that there was an opportunity in January/February 2004 for a HCV diagnosis to have been notified to S

88. In 2019, GRO-B and I we were in the Infectious Diseases Unit at Glasgow Western Infirmary ("Glasgow Western"), Dumbarton Road, Glasgow, G11 6NT, when GRO-B was looking through the news on her phone. She came across a news article on the Infected Blood Inquiry ("IBI"). It was like a light bulb moment. S had received a number of blood transfusions throughout his medical treatment. Could he have gained his HCV from a contaminated blood transfusion? In an attempt to uncover answers GRO-B and I attended one of the IBI hearings in Edinburgh, Scotland.

89. For the first time GRO-B and I felt at home. She had said that she felt that all the people in the room at that point in time had been going through the same experiences as we had. Also, that people were acknowledging what we were going through.

90. As a result of a conversation with one of the members of staff at the IBI at the hearing, she advised us to get hold of S medical records in an attempt to determine the cause of S HCV.

91. Contained within a copy of S medical records, was a Virology Report dated 04 February 2004, GRO-B GRO-B sourced at GRO-B Renal Dialysis, GRO-B Renal Consultant (exhibited below, at **WITN4730004**). The report states as follows:

> *"Hep B surface antigen: Negative*
> *Hepatitis C screen: REACTIVE*
> *HCV PCR: Insufficient*
> *Insufficient sample for HCV PCR testing*
> *Please send another specimen of clotted blood."*

92. We were shocked; the report had shown that on 21 January 2004, S had tested positive for the presence of HCV. This was the first time at which we had gained knowledge that a test for HCV had taken place in 2004. We had not previously given our consent for this test to take place, nor, had S told us that he had undergone a blood test for the presence of HCV. Importantly no one in authority had deemed it necessary to inform us of the infection or the fact that they were requesting a further sample for diagnosis.

93. Why had a test for HCV been undertaken in 2004 without our knowledge, and why had the results surrounding S HCV diagnosis not been relayed to us. There was no follow-up.

94. Also contained within the report, it had stated that more blood was needed to be taken for further testing to take place. There is no record in S medical records that had shown that more blood was taken, or, that another test had taken place. If so, why was no further blood test done to confirm the diagnosis?

95. Why did it take fourteen years between the HCV test in 2004 having returned a positive test result, and October 2018 for an official diagnosis to be made? Alarm bells started to ring in our heads GRO-B a GRO-B could have told us about the test having taken place, and the respective positive result. He continued to provide correspondence with S GP surrounding the symptoms he had been experiencing around 2004, but failed to mention testing for HCV having taken place.

96. This is confirmed within a letter dated 23 January 2004 from GRO-B GRO-B GRO-B to GRO-B GRO-B exhibited below at **WITN4730005**). GRO-B does not mention that S had undergone an HCV test. The letter states as follows:

> S *was reviewed. He was telling me over the last two months he has been having intermittent bouts of right anterior chest pain localized to the mammary region and described as "jaggy." The symptoms are not changed by respiration, coughing or alteration in posture and there is no radiation. His chest was clinically clear and his medication is unchanged. I felt this was not consistent with cardiac or pericardial pain and I suspect it may be related to his overall posture. He is in the process of being referred to the Western Infirmary but I wonder if you would be good enough to prescribe Hyoscine hydrobromide one patch every 73 hours in an attempt to reduce the salivary volume which is very troublesome. His plasma creatinine is stable at 220 umol/1.*"

97. This would fit in with why, when we had asked GRO-B why S could not receive care at Stobhill as it was closer, but at GRO-B as they had an Infectious Diseases Unit. He failed to tell us that S had tested positive for HCV.

98. Thereafter, we had tried to determine the point at which S had been infected with HCV. Through a process of elimination, the only possible cause of his infection, was the number of blood transfusions he had received between 1984 and 1989, at GRO-B

99. We do not know at what point S was given a contaminated blood transfusion, or, whether it may have been the first point at which he was treated on the date of his birth on GRO-B 1984. S had been given numerous blood transfusions between 1984 and 1989, of which, it would be difficult to determine the implicated batch.

100. Within a document contained in S medical records, dated 23 August 1988, (exhibited below at **WITN4730002**) there is a list of the blood transfusions that S had undergone between 05 May 1988 and 27 August 1988. This states as follows:

*"<u>Blood Transfusion</u>*

| | |
|---|---|
| *5.5.88* | *Hb. 6.1 – 1 unit* |
| *9.5.88* | *Hb. 9.7* |
| *12.5.88* | *Hb 9.1 – 1 unit blood loss during insertion, new subclavian long line.* |
| *14.5.88* | *Hb 9.7* |
| *18.5.88* | *Hb 9.1 – 1 unit packed cells 20.5.88* |
| *23.5.88* | *Hb 11.5* |
| *24.5.88* | *Hb 10.3 – ½ unit blood* |
| *25.5.88* | *Hb 11.2 – further longline inserted* |
| *26.5.88* | *Hb 7.9 – 1 unit blood* |
| *27.5.88* | *Hb 8.5 – further unit of blood with further long line insertion.* |

| | |
|---|---|
| *6.6.88* | *Hb 5.7 – 1 unit blood* |
| *10.6.88* | *Hb 12.2* |
| *28.6.88* | *Hb 8.5 – 150ml. packed cells* |
| *2.7.88* | *Hb 12.8* |
| *11.7.88* | *Hb 9.1 – 1 unit 13.7.88* |
| *1.8.88* | *Hb 7.0* |
| *3.8.88* | *Hb 7.3 – 1 unit* |
| *11.8.88* | *Hb 10.9* |
| *27.8.88* | *Hb 9.7 "* |

101. Prior to each blood transfusion S had undertaken between 1984 and 1989, we were not provided with any information or advice beforehand, of the associated risks of blood borne infection. We did not know anything about contaminated blood at the time. We had 100% faith in the National Health Service ("NHS").

102. Between the point of S 'official' diagnosis in October 2018, and his death on GRO-B 2020, S health had taken a gradual deterioration.

103. We had noticed that S stomach had become distended. We pointed this out to his GP GRO-B and he had stated this it was just the shape of S body. In response I had told GRO-B that this was not the case, but instead, his stomach is enlarged. He did not want to acknowledge his stomach.

104. By November 2018, we had noticed that S was really not doing well with regards to his health; in particular his mental health S was constantly tired and paranoid. We had to put alarms on all the doors in the house and put up cameras. We told him that we were going up put a camera facing his hospital bed in his room. He would get up in the middle of the night and undress himself. Fall on the floor; make his way to the front door etc. When we questioned why he had done this, he had told us that he was getting ready to go to school. He was thirty-three years when this started.

105. Thereafter, his paranoia had persisted for a long period of time, so we sought medical assistance from Monkland's.

106. After S had undergone testing, the results had returned as showing that he had hepatic encephalopathy, which is a decline in brain function that occurs as a result of severe liver disease. In effect, his brain had been poisoned GRO-B had recognized his symptoms from the research she had done, she knew it was from S damaged liver; his brain was being poisoned by the toxins in his blood.

107. S was placed on anti-biotic tablets thereafter and had undergone a number of scans.

108. Thereafter GRO-B carried out a lot of research into S HCV infection, and the long-term implications it would have on his health. One of the possible side-effects of HCV was hepatic encephalopathy. At a face to face consultation with one of the doctors in charge of S care at Monkland's, we asked the Doctor to confirm what stage S liver was, GRO-B said is he at end stage? and she said yes GRO-B had to ask; there was no explanation, the Doctor just walked away.

109. In January 2019 S was cleared of the hepatic encephalopathy.

110. Between January 2019 and May 2020 S was back and forth to hospital.

111. In September 2019 S had experienced pain in his shoulder. We sought medical assistance from Monkland's, to which, on 23 September 2019, S had undergone a liver scan to determine the condition of his liver.

112. Whilst S was not ever diagnosed with liver cirrhosis, the world fibrosis was being thrown around. I knew he had cirrhosis due to the side effects. They did a fibroscan and result had returned as showing 25. S did not undergo an invasive liver biopsy due to the associated risk.

113. The medical staff appeared to be extremely reluctant to tell us the state of S liver or even use the word cirrhosis; to us his condition was

underplayed. Even if the word Cirrhosis appeared on a letter, verbally they did not acknowledge it.

114. Thereafter, we were told that the liver can heal itself. I thought is that so? He was yellow. He was beyond that point. I feel that we were being misled about the state of his liver. It was horrific. We felt that we were the only people who could see how bad he was.

115. Within a letter dated 26 September 2019, from Dr Alan T Clarke, Consultant Physical and Gastroenterologist, Monkland's Hospital, Monkscourt Avenue, Airdrie, ML6 0JS to Mr [redacted] (exhibited below at **WITN4730006**), it states the following:

> *"I have the results of your ultrasound scan performed on the 12th September 2019. This shows a bright liver in keeping with liver disease, although there is no problem such as liver cancer seen which is reassuring. Your right kidney has a small simple looking cyst which is not of any concern. There was some enlargement of the spleen in keeping with cirrhosis, which is not unexpected. There is no other abnormality on your scan which is reassuring."*

116. On 07 January 2020 [redacted] was admitted to Monkland's as his health had declined. This is confirmed within a document contained in [redacted] medical records, dated 31 January 2020, entitled "Discharge Letter and Prescription" (exhibited below, at **WITN4730007**). The letter states the following:

> ***Clinical Progress:***
>
> *[redacted] was admitted from clinic with general decline, jaundice, confusion and lethargy. He had deranged LFT's and was felt to have decompensated liver cirrhosis. His renal function was at baseline. Neurologists suggested triple bromide could be contributing to confusion so this was stopped and he remained seizure free. An USS and MRCP did not allow good vies of the CBD. He was treated for an*

*infection of unclear source whilst an IP. He has been referred to Edinburgh as an OP for consideration of transplant."*

117. On 01 Feb 2020 S was discharged home from Monkland's.

118. On 17 March 2020 we attended the liver transplant out patient clinic at the Edinburgh Royal Infirmary. S was seen and we were in and out very quickly with the news that no transplant could be done as his liver was so bad.

119. In April 2020 S was experiencing pain in his shoulder, persistent tiredness, and difficulty breathing. We rang Monkland's for medical assistance. As a result of Coronavirus ("Covid-19") lockdown restrictions, were told that we had to take S to the A & E Department to gain medical assistance.

120. 04 April 2020, eventually we saw a doctor at Monkland's. We were told that if S Covid test came back as positive, they would take him onto a Covid ward and we would not be able to see him again. Thankfully his test was negative S was placed onto a ward at Monkland's. They said that due to Covid-19, we were not allowed onto the ward to visit him. This was the first point in his life that we had ever been separated from S

121. Each day, we would bring his pyjamas to the ward. When the Sister saw GRO-B she told the Sister that she had not ever been separated from her son before, to which the Sister let her in straight away. For the next two weeks, GRO-B was allowed to visit S in for ten minutes at each meal time, and to bring his pyjamas.

122. Thereafter, we had noticed that his weight had gone up from a size small to extra-large. (In 2004 S weighed 40.7Kilos) This was attributable to the medical staff in charge of his care giving him seven bags of fluid as treatment. GRO-B knew that they were giving him too much fluid, so she raised this with them when she could. Just looking at him, he was getting larger and larger. The medical staff agreed to reduce his dosage thereafter.

123. Dr Hand, Renal Consultant at Monkland's had phoned us to tell us that S liver cirrhosis and kidney were working against each other. Also, that he was in 'palliative' care in a round-about way.

124. The first time we could go to visit S Dr Hand had asked S whether he wanted to undergo dialysis. However, attached to this question was a caveat. If he chose to undergo dialysis, he would need to go to theatre to have a line fitted, and if survived the surgery; which he did not think he would, he will be very ill and he would die a very painful death.

125. S decided not to go ahead with the dialysis. He told Dr Hand that he wanted to see his nieces and nephews grow up. I believe that the doctor took this the wrong way S said he wanted to fight, but they took his comment as to mean that he did not want to undergo the surgery.

126. On 14 April 2020 S was discharged home for palliative care. He was told that he would receive care from a number of Macmillan nurses which had been put in place.

127. Within a document contained in S medical records, dated 14 April 2020, from University Hospital Monkland's, Monkscourt Avenue, Airdrie, ML6 0JS, entitled "Discharge Letter and Prescription," (exhibited below, at **WITN4730008**), it states the following:

> ***Clinical Progress:***
>
> *"Admitted with shortness of breath and increased oedema in abdomen and thighs likely due to decompensated liver cirrhosis. During admission. S fluid overload was managed with oral diuretics during admission. S furosemide was changed to alternate days with the option to increase if oedema was to return. During admission S had a seizure. His triple bromide had been stopped due to deranged LFTs but was restarted.*

> *During admission, any discussions were had with S and his parents. The decision was made that S would be for a palliative discharge and was not for further re-admissions to hospital and no further regular blood monitoring. His renal function had declined and he would not be an appropriate candidate for dialysis due to poor QOL. Therefore, the decision was made between Dr Clarke, Dr Hand and S that he would be for best supportive care at home."*

128. From the point at which S was discharged home on 14 April 2020, he did not receive any care from a Macmillan nurse, we did try but it never happened. We were left to fend for ourselves.

129. A week later, GRO-B rang GRO-B at home to ask if she would sign the non-resuscitation letter put in place for S She told the Dr that she did not want to sign the letter as this was not something we wanted to think about now. I asked whether a Macmillan nurse would be visiting us at our home to care for S of which we were told yes, this was the case. Thereafter, still, a Macmillan nurse had not visited our home to care for S

130. On 01 May 2020, we had noticed that S health had perked up, he had asked me whether he could have a bag of chips from the chip shop for his dinner. He was able to sit up and eat his bag of chips as normal. After that he went to sleep as normal. This was to be his last meal.

131. On the morning of 02 May 2020 GRO-B woke S up as she would normally do to bathe him. He had told her that he was feeling a bit tired, but that he was okay. Whilst he was in the bath, she noticed that he had fallen back to sleep. After GRO-B had attended to his personal care, he said that he felt better and that he was going back to bed. He didn't want his Xbox, which was unusual. He just wanted his music on. He slept the whole day and he was not eating.

132. Later that day, GRO-B and I knew by the look of S that there was something really wrong with regards to his health. At that point I tried to phone

the Macmillan nurse as we knew that we were not able to do too much for him at that point. I phoned the number of the Macmillan nurse, and I did not get through. Eventually, I spoke with three different nurses; they put me through to their doctor.

133. She told me that S case had not been registered with Macmillan, I explained that he had a peg and she said if you can get fluid into him he should survive until Monday, (this was Saturday evening) he could then be referred. She also mentioned that she would not have prescribed the drugs he was on.

134. S woke up, and we said to him we are lost we do not know what to do. He told us that he was not going into hospital as he did not want to die in hospital. We rang the doctors at Monkland's and they had reaffirmed the agreement previously made with S in that he was sent home for a reason. This was palliative care. He was not to go to the hospital for anything. They said unless he was dead, they couldn't do anything and send anyone out. We were crying out for help and we received no help. We felt completely helpless.

135. Before S passed away GRO-B had asked him if he wanted lifting up? He was patting his chest. He nodded. She then asked if he wanted a drink and he nodded and took a few small sips. We did not know what his signal meant, or whether it meant that he was having chest pain.

136. GRO-B asked S whether he was okay, to which he looked straight forward and he put his hand out for her to hold, he squeezed her hand very tightly GRO-B was holding S and his face was resting on her. He made a couple of gasping sounds and she knew in that moment that S had gone. GRO-B shouted to me that she thought he was 'away'. We just held him in our arms thereafter. We did not know what to do. We were lost and on our own.

137. GRO-B 2020 at the age of thirty-five years old, at 22:28 hrs S passed away. After his passing, we phoned his brother and sister, and they came down.

138. The phone rang and it was a doctor from Monkland's. We had told them they were too late as he had already passed away. They sent nurses out straight away to our home. Dawn Mcintyre Community Staff Nurse registered health professional confirmed his death at 00:30 hrs on GRO-B 2020.

139. I phoned the undertakers. We told them that S was cleared of HCV, but we had always made a point of being up front with everyone with regards to his infection.

140. As the undertakers had taken S down the drive in a body bag to the mortuary van, I said to GRO-B don't look, to which she replied stating something along the lines of "*I brought him into this world, I will watch him go out of this world*." The only blessing he got was that he died in his home surrounded by his parents.

141. No post-mortem was undertaken.

142. Within a Medical Certificate of Cause of Death, dated GRO-B 2020, Certified by GRO-B exhibited at **WITN4730009**) it states the cause of S death as follows:

> ***"I. Disease or condition directly leading to death***
> *(a) End Stage Liver Failure - 2 months*
>
> ***Antecedent causes*** *– Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last*
>
> *due to (or as a consequence of)*
> *(b) Cirrhosis of liver - 10 months*

*due to (or as a consequence of)*
*(c) Hepatitis C - 1 year 4 months*

***II Other significant conditions** contribution to the death, but not related to the disease or condition causing it*

*Chronic Kidney Disease 35 years 11 months*
*Cadaveric Renal Transplant 33 years*
*Renal Agenesis and Dysgenesis" 35 years 11 months*

143. The undertakers were very professional. We had our funeral under the Covid-19 rules and regulations on the GRO-B 2020. S was cremated and his ashes are with my brother at his grave.

## Section 3. Other Infections.

144. As far as GRO-B and I are aware, we do not believe that S have received any other infection or infections other than HCV as a result of being given infected blood. On 7 January 2020. S had been tested for the presence of HIV. We were never told the result.

145. S had been tested for the presence of Hepatitis B ("HBV"), to which the results of the test had returned as negative.

## Section 4. Consent

146. GRO-B and I do consider that throughout S treatment and care, there are periods in which he had been tested and treated without having given prior consent, or without adequate and full information being given to us. This relates in particular to five occasions.

147. Firstly, as previously mentioned, on 26 June 1984 S was given a blood transfusion as treatment at the age of GRO-B month old. At no point, were GRO-B and I told that there was a risk of blood borne infection as a result of the blood transfusion. As a result, we were not able to provide fully informed consent.

148. Secondly, on 28 January 1987, we had attended a face to face consultation with GRO-B when we were told that S had to have a CAPD fitted permanently. He had asked us for our consent, but he had also stated that if we did not give consent, he would still go ahead anyway as it was to save his life. I understand that his was an emergency situation, and effectively saved his life, but, I would have suspected that consent always had to be obtained from parents prior to treatment undertaken.

149. Thirdly, in 1988/1989, S had undergone dialysis and had been given various units of blood during a blood transfusion throughout his stay at GRO-B We did not sign any consent form for such blood transfusions to have taken place.

150. Then, on 21 January 2004 S had tested positive for the presence of HCV. This was the first time at which we had gained knowledge that a test for HCV had taken place in 2004. We had not previously given our consent for this test to have taken place, nor, had S told us that he had undergone a blood test for the presence of HCV.

151. Lastly, on 16 October 2018, a further blood test was taken. This time, it was a test for the presence of HCV. We were not told that the test had taken place.

152. We do not consider that S had been tested or treated for the purposes of research.

## Section 5. Impact.

### Mental/Physical Effect.

153. GRO-B and I do consider that S HCV had a vast impact on the deterioration in his health. As you can see S had some severe health issues, however, his death was caused by the HCV, and the damage it had done to his liver.

154. After S second kidney transplant in 1987, we had also noticed that S was experiencing one illness after the other. He was always tired, lethargic, fatigued and cold in temperature. His face would still be drooped on the right side as a result of his stroke, and he remained reliant on his wheelchair. We question as to whethe S was in fact battling HCV from a very early age.

155. Although at the date o S death he was thirty-five years old, physically, he did not look his age, he aged dramatically in his later years.

156. In January 2019, S was diagnosed with Diabetes Type 2. Whateve S consumed, it did not make a difference. We think that his eye sight was affected as a result of his diabetes. We have since come to learn that Diabetes Type 2 is a chronic symptom of HCV.

157. We also believe that S HCV had a drastic effect on his liver. On 23 September 201 S had undergone a liver scan to determine the condition of his liver. When the results had returned, whilst S was not ever diagnosed with liver cirrhosis, the world fibrosis was being thrown around. I knew he had cirrhosis due to the side effects. They did a fibroscan and the result had returned as showing 25. S did not undergo an invasive liver biopsy due to the associated risk.

158. Withi S Medical Certificate of Cause of Death, dated 04 May 2020, Certified by GRO-B exhibited below, at **WITN4730009**), it had shown

tha S had Cirrhosis of the liver for ten months, and HCV for one year and four months. Through research GRO-B had found out that for Cirrhosis of the liver to develop, HCV must have persisted in the body for a period longer than the aforementioned. Therefore, it cannot be the case that S only had HCV for one year and four months.

## Treatment

In October 2018 S was admitted to the Infectious Diseases Unit at Monklands. He was placed on a sixteen-week course of Mavira. This course of treatment consisted of one table taken orally once a day S was not told about the potential side effects of his treatment with Maviret. He became quite aggressive and confused. Brain fog aptly describes this. He also had bad mood swings and headaches.

159. For the first two weeks of starting his course of treatment, he remained in hospital. Thereafter, he was discharged home, and returned to Monklands for check-up appointments to track his progress on his treatment.

160. GRO-B and I had noticed that S was not getting any better with regards to his health. When we questioned this with the doctors in charge of his treatment at Monklands, we were told that everyone else was doing well on the treatment, and that could not have been the case.

161. In addition to the aforementioned mood swings and behaviors S experienced a constant feeling of tiredness, fatigue, and nausea. He also experienced itchy skin which would bleed profusely.

162. In February 2019, S finished on his course of treatment with Maviret. We noticed tha S was still experiencing itchy and yellow skin. We did not think that the

treatment had an effect on the level of his HCV in his blood. That was, until S had undergone a test on 07 May 2019. When the results had returned on 10 May 2019, it had shown that the levels of HCV in his blood were not detectable. In the absence of RNA, there is no evidence of ongoing hepatitis C infection. We do not know S genotype or what his HCV viral load was. This information has never been passed onto us.

## Impact

163. The loss of S has had a huge impact on us as a family. We have a void. As a mum I think GRO-B has been affected the hardest out of our family as a result of S HCV diagnosis and subsequent death. She had given birth to S and had, in effect, cared for him everyday for thirty-five years.

164. At one point, before S deterioration in his health, she would tell me that she thought our life was so good. We were so family orientated, and we lived in such a happy house. if she could go around with one biscuit in the hand and a pinafore in the other, she would have lived just like that forever.

165. Now, we have a void in our lives which will never be filled. GRO-B is trying to get back to her old self, but has soon realised that she has to learn to live with the new her following S passing. As her way of coping with his death, to this day she finds herself going into S room and laying out her pyjamas and deodorant on his bed. She dusts around his room and chats to him as if he was sitting in his bed. She would often say to S something along the lines of "*look what your father has done to the garden*." She can still smell S on his clothes.

166. She often asks me whether I think that she is going mad. I would tell her that this was not the case. If she finds comfort in doing this action, then this is her way of grieving for the loss of her son.

167. GRO-B would love to sit down with the children and talk abou S but she does not think that she is ready just yet. She has only been able to go to visit his grave three times since his death.

168. GRO-B has lost all her confidence, and her life has effectively vanished. She was a completely different person prior to S death. She has lost a lot of friends. She has a feeling that they all feel a bit awkward around her and do not know what to say. They would dance around the truth.

169. Afte S death, I cannot see my children in the light I used to see them in. Our family will never go back to what it was before S passing. There was always laughter and happiness in the home. We have a missing link. I got to the point that I did not care if I woke up in the morning. We have two other children's and grandchildren who we now have to live for, but when you are fresh in the grip of grief, you are hurting and you do not think logically.

170. When S passed, I could not eat. I started drinking fresh orange and Lucozade, which, as a result, I was diagnosed with Type 2 Diabetes. I am currently incontinent depending on the medication I take. I have to plan everything I do as a result. Whenever I eat, I have to be near a toilet, which is difficult due to the profession I am currently in.

171. Alongside GRO-B and I, our daughter GRO-B has been impacted by S passing. Prior to his death, they would spend great lengths of time on the phone to one another and facetiming. Due to them being so close, she took his death really hard and has found it hard to get her life back on track. She has not been able to go to S grave. She has recently had a new baby in April 2021, so this has worked to take her mind off of his death.

172. GRO-B was also impacted by S passing. He has always tried to be a man's man, and not show his emotions. Only recently did he tell us that he had been going up to S grave. Before this, he could not attend his grave as he was still grieving.

173. Our grandchildren found it hard to comprehend that S had passed. Recently, one of our granddaughters said to GRO-B that they had a dream about S which as a result, they now realise that he is dead.

174. Our eldest grandchildren and S were so close. They would spend so much time together; on the Xbox and watching scary movies together. We would constantly hear laughter when they were together. They were more like brother and sister.

175. As a result of S health and his reliance on his wheelchair, he found it difficult to be able to go anywhere properly such as to the local town. If he wanted to go out independently, we would use the Dial-a-bus service for persons with disability who were unable to use public transport. This allowed S to be able to meet up with friends in our local town, or carry out other activities such as go shopping.

176. S ill-health and subsequent death had a substantial financial effect on the family. I was on a zero-hours contract prior to his death. Whilst this allowed for me to care for S it also meant that I was not guaranteed a set income each month. After his death, I found myself unable to work as I was grieving. However, it soon became apparent that I had to go back to work due to financial constraints and a need to provide for the family.

177. GRO-B was, and still is, unable to work both mentally and physically.

178. Upon S death, he did not have a Will. His estate is currently going though the courts and we had to hire a lawyer. The DHSS have said that they have a claim to the SIBBS money we had been awarded for S That has held up the distribution of his estate. The solicitor states that the DHSS have no claim but it is holding up the process.

179. S ill-health and HCV infection had an impact on his education. GRO-B and I believe that S had been infected with HCV as a result of contaminated blood received between 1984 and 1989; of which, it would have been prior to having attended primary school.

180. Whilst S was able to attend primary school, the teachers soon realised that they were unable to care for his illness whilst he was in the school setting. GRO-B and I made the decision to move S to a school, which would meet his needs, so that he could be adequately cared for, and receive a good education. He loved it there and thrived.

181. However, upon attending his secondary school called GRO-B GRO-B we soon realised that his health had taken a turn for the worst. He did not appear to thrive like the other children. He was constantly experiencing tiredness, fatigue and nausea. He was also experiencing illness after illness as his immune system was not in a great state of health. This affected his ability to do well in his education.

182. In 2000, at the age of sixteen years old, S attended GRO-B GRO-B where he had undertaken a two-year course. This course was aimed to teach him everyday living skills such as how to pay bills, cook, clean and to teach him independence. In 2002, at the age of eighteen years old, S left college.

183. S was not able to gain any form of employment as a result of his ill-health. In S 20's, he was unable to gain access to carers. He was however, given a social worker, who had arranged a careers coach to attend our home. As soon as the careers coach attended our home, she had stated something along the lines of "*why am I here*?" In response, we did not know why. She had told us that S was unable to gain employment due to his ill-health.

184. From S early 30's he gained access to regular carers, who would take him out twice a week.

185. I cannot say that we experienced any of the stigma attached to HCV as an infection.

## Section 6. Treatment/Care/Support

186. I do consider that over the course of S treatment he had received, that he had faced difficulties in obtaining adequate treatment from a number of NHS medical practitioners.

187. When S was admitted to the infectious disease ward in 2018, the nurses who were in charge of his care on the ward he resided on were very lazy. GRO-B would constantly complain at how lazy they were, and that they were not providing an adequate level of medical care for S This would mean that S would last for hours without being given care from the nurse, of which, he would often experience split colostomy bags. The nurses were quite cruel to him.

188 GRO-B came to an agreement with the staff, she told them that if she could do his personal care during the day, then the nurses would need to give personal care through the night when she was not able to be there. This did not happen. The care S received was unacceptable. We felt helpless as parents.

189. In addition, I feel that my GP GRO-B would provide us with fluctuating levels of care. In 2018, we sought assistance from GRO-B after we had been referred by the Renal Consultant at Monkland's.

190. In a meeting with GRO-B to discuss his health. S was sitting in his wheelchair, yellow in colour, with GRO-B big scarf around him to keep him warm GRO-B ad asked whether paracetamol could be prescribed as we had been referred from Monkland's. Upon hearing this, he told us that he could not prescribe paracetamol, and that he would refer us back to the Renal Consultant at Monkland's.

191. He did not even acknowledge S the whole time we were in the consultation room. He did not even say to S how are you doing, how are

you feeling. In hindsight it appeared that the Doctor did not acknowledge S we felt that this was due to his HCV.

192. When we returned home from this face to face consultation with GRO-B asked S whether he had noticed that there was something wrong with our GP? We wondered whether this reaction or behavior was as a result of S HCV diagnosis and GRO-B religio?. That day, he was different. He had previously been a really good GP. It left a bad taste in our mouth S didn't see this as he told us he had been asleep!

193. Afte S HCV diagnosis we never attend any dental care for S I am therefore unable to say whether or not they would have refused treatment.

194. Both GRO-B and I were tested for the presence of HCV. When the results had returned, it had shown that we had both tested negative for HCV. We sought testing ourselves.

195. Neither GRO-B or I were offered counselling by the medical profession as a result of S HCV diagnosis or his subsequent death S was also not offered counselling as a result of his diagnosis.

196. My employer did tell me to ring the company's counsellor, I did this but to be quite honest the young girl was not in a position to help me. She was out of her depth.

## Section 7. Financial Assistance

197. Afte S HCV diagnosis on 19 October 2018 GRO-B did some research on Google surrounding the infection. During the process of research GRO-B had come across the Infected Blood Inquiry ("IBI") website. It was as a result of coming across this website, that GRO-B had been notified of the provision of financial assistance by the Scottish Infected Blood Support Scheme ("SIBBS").

198. Financial assistance for S HCV had not been recommended to us at the point of S HCV diagnosis or through the medical profession thereafter.

199. On 10 December 2018 GRO-B downloaded the application forms to apply for financial assistance from SIBBS in S name. During the process of filling in the application form, it had stated that S and GRO-B needed to give the application forms to the person who was in charge of S care for his HCV infection; Dr Kennedy at Monklands. Thereafter, the application forms had to be given to GRO-B Renal Consultant, Renal Transplant Clinic, Monkland's Hospital.

**200.** In late December 2018, GRO-B gave the application forms to Dr Kennedy so that he could fill in the respective areas with regards to S HCV. Six months passed. I exhibit a copy of the front page of the application form, which I note is dated 10-12-2018. **Exhibit WITN4730014**

201. In January 2020 GRO-B and S attended a face to face consultation with GRO-B regarding Colin's health. During conversation they asked GRO-B whether he had got word back from the SIBBS regarding their application for financial assistance. In response, he told them that he could not make the application on S behalf, but instead, they had to make the application. GRO-B questioned him on what he meant by this, to which she said that it had stated on the application form that they had to get evidence from the medical professional in charge of S HCV care. He had asked GRO-B what forms I was talking about?

202. GRO-B proceeded to tell them that he had thought that we were looking to sue the Health Board, so he had previously made inquiries into this process. GRO-B had told him that she meant the SIBBS application forms, to which he had stated that he had not received any forms.

203. That night GRO-B and S went home and re-filled in the application form for financial assistance from SIBBS. The application forms were given to Dr GRO-B the next day.

204. In January 2020, the application forms for financial assistance were submitted to SIBBS.

205. On 18 February 2020, we received a reply from SIBBS stating that our application for financial assistance had been successful. Within a letter from Sally Richards, Scheme Manager, Scottish Infected Blood Support Scheme, National Services Scotland, to Mr S (exhibited below at **WITN4730010**), it states the following:

> *"I refer to your recent application to receive Advanced (Stage 2) Hepatitis C payments from the Scottish Infected Blood Support Scheme. I am pleased to confirm that we have completed the assessment of your application and it has been approved.*
>
> *Under the rules of the scheme you will receive a £70,000.00 lump sum payment. You will also receive monthly payments of £2,250.00 from the scheme, on or around the 15th of each month, starting in March 2020. Your first monthly payment however, will be £4500.00 for the months of February and March. Your lump sum payment will also be made on, or around the 15th March 2020."*

206. Within a letter dated ("as per post park"), from SIBSS Payment Team, Scottish Infected Blood Support Scheme, National Services Scotland, to Mr S (exhibited below, at **WITN4730011**), it states:

> *"I am writing to inform you that your SIBSS regular payment will be increased by 1.7% from April 2020. See table below for revised payments: –*

| *Current Annual Amount* | *New Annual Amount* | *New Monthly Payment* |
|---|---|---|
| *£20250* | *£20594* | *£1716.17* |

207. When we received the financial payment, we were able to buy S a lightweight wheelchair. He was only able to use it once before his death on GRO-B GRO-B 2020.

208. Upon S death, we informed SIBBS. He was due another two payments up until June, which they paid into GRO-B bank account.

209. We are currently in the process of sorting out S estate. The DHSS have stated that they have a right of claim over the payment S had received from SIBBS. This debate has meant that the process of sorting out his estate has been delayed.

210. In May 2021 GRO-B received a phone call from Dr Kennedy out of the blue. He had stated something along the lines of "*Hi* GRO-B *you won't remember me, but I cared for* S *years and years ago. I did not actually realise that* S *was dead. Did you know that you are entitled to financial compensation?*" In response, GRO-B said "*right?*" To which Dr Kennedy said something along the lines of "*I am just telling you. Also, did you get anything from the form you gave me in 2018?*" GRO-B responded that she did remember him and that it was not years ago that he had treated S GRO-B was angry at this call.

211. After putting the phone down GRO-B said to me why was he ringing me? Retrospectively GRO-B and I believe that the only possible explanation for why Dr Kennedy could have telephoned us all these years later, was that he had found the application forms for SIBBS from 2018, and that he had realised that he had not sent off the application form on our behalf. He must have tried to right his wrong and try to ring us for his own conscience.

212. It was such a shame that the original application in 2018 had not been processed. Had we had that money then we could have done so much more for S The money came far to late.

## Section 8. Other Issues

213. GRO-B and I believe that there has been an element of cover-up with regards to S medical records. This surrounds the period of 1984 and 1989, which relates to the period between his birth on GRO-B 1984 and the age of five years old.

214. In 201 GRO-B and I attended GRO-B to request access to S medical records, to which we were told that a nurse was currently working on it. I asked what they meant by this, to which I was told that a nurse was going through his medical records getting rid of the duplicates, as they had previously complained about the size of S files and that they were very heavy to carry.

215. In 2019 GRO-B and S requested access to S medical records from GRO-B This was because the Neurologist Department wanted to look at his medical records in relation to his care.

216. On Saturday 24 August 2019, we received the medical records GRO-B had previously requested from GRO-B However, upon inspection of the records, we had noticed that a number of records were missing; specifically in relation to the years of 1984 to 1987 inclusive.

217. On 26 August 2019 GRO-B had sent an email to GRO-B Administrative staff member at GRO-B in relation to the missing medical records. They had requested that the respective missing date range be sent to them. This is exhibited at **WITN4730012**.

218. On 09 October 2019 GRO-B eceived a reply from GRO-B which stated that all records held by GRO-B had been provided to them. For NHS Lanarkshire records, would need to contact them directly as they were a different Health Board.

219. On 23 November 201 GRO-B replied to GRO-B email. This is exhibited at **WITN4730012,** and it states as follows:

> *“H GRO-B*
>
> *You have stated that my records from 1984 1985 1986 and 1987 are not available.*
> *These were crucial records. Can you explain if they are getting held elsewhere or did someone destroy them. It must be on file as to the whereabouts of these missing records.*
> *I can’t understand why all other records are there apart from these 4yrs. I would like you to answer a few questions:*
>
> 1. *Have they been destroyed, who would have authorised them to be destroyed and why.*
> 2. *If they are missing, when did they go missing, how did they go missing, and where did they go missing from, and who was the last person that signed them out.*
>
> *If you cant answer these questions could you tell me who to contact and what dept as someone must know what happened to these records as they just don’t disappear.*
>
> *Regards*
>
> GRO-B

220. Thereafter, we did not get any further correspondence from GRO-B

221. After our initial conversation with Roger Milburn, Deputy Lead Investigator of the IBI in November 2020, GRO-B and I sent a letter to Gartnavel dated 3rd November 2020 requesting the first four years of S medical care. And subsequent treatment.

222. On 05 November 2020, we received a letter from Legal Aspects Team, 2nd Floor Admin Building, Gartnavel Royal Hospital Campus, 1055 Great Western Road, Glasgow, G12 0XH, (exhibited at **WITN4730013**). This states that my correspondence regarding a request to obtain S medical records relating to GRO-B 1984 and 1987 had been acknowledged. Also, that they had one calendar month to comply with my request for medical records.

223. We have not since heard a reply; despite sending the letter twice. We sent the letter recorded delivery which shows that the letter had been received.

224. I do not understand why the medical records relating to the first four years of S life have been destroyed, but the other are still there. Why else would they have destroyed the medical records, other than to cover-up the notes relating to the blood transfusions he received in this period, and their involvement in S paralysis.

225. We contacted the IBI on 16 October 2020, as we wished to give S a voice. Just because S is no longer here with us, it does not mean that he does not have a voice. We are his voice. Even when he was here, he was not well enough to have a voice.

226. I wish for the IBI to gain a recognition of what the NHS and the Department of Health ("DHSS") did to S and thousands of other people in his position. We want them to be recognised that they were at fault. I feel that they should not get away with their involvement in the Contaminated Blood Scandal. Morally, how can they get away with this? I feel something needs to be done. Their involvement needs to be made public. I have been following the IBI hearings and some of the stories are unbelievable.

227. We do not know at what point S had been infected, but it was sometime in the 1980's. We have seen documentation to show that he had tested positive for HCV in 2004. It was not until 2018 that he had been officially told that he had HCV. For fourteen years, the medical profession had potentially known

that he had HCV. There was no medical intervention for that period or treatment for his liver. When he got treatment, it cleared his virus.

228. If the medical profession had treated him in 2004, I believe tha S would still be here. It is my belief that if he had not been given the contaminated blood, he would still be here with us today.

229. The doctors in charge of care, they watched my children grow up and become a man GRO-B knew all of my children, and he knew the test result and never told us. He knew what loving parents we were and are, if something could be done we taught ourselves to care for S

230. It is a paradox. The medical staff saved his live for all of the medical defects he had throughout his life, but, they also took his life in the end through contaminated blood.

231. We believe that he was infected at an early age. This was why he did not thrive throughout his teenage years. We were always there fo S and we did the best we possibly could do for him. We have had no help throughout S life and after his death.

232. It has been one year since his death and we as a family, are still hurting. We will be grieving our loss of our wonderful son for a very long time to come. He has left such a large hole in our lives. Nothing comes close to losing your children. You should never have to bury your children. They teach you now to nourish your children, keep them warm. What they do not prepare you for, is letting go.

## Statement of Truth

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

Signed GRO-B

Dated 21-7-21

**Table of Exhibits:**

| **Date** | **Notes/ Description** | **Exhibit number** |
|---|---|---|
| 23 August 1988 | Document, contained in GRO-B medical records. | **WITN4730002** |
| 06 June 2017 | Letter, from GRO-B Renal Transplant Clinic, University Hospital Monkland's, Monkscourt Avenue, Airdrie, ML6 0JS, to Mr S entitled GRO-B – Renal Transplant Clinic – Tuesday 6 June 1017." | **WITN4730003** |
| 04 Feb 2004 | Virology Report, dated, Regional Virus Laboratory, Gartnavel General Hospital, PO Box 16788, Glasgow G12 0ZA, sourced at GRO-B Renal Consultant | **WITN4730004** |
| 23 January 2004 | Letter, from GRO-B Consultant Paediatrician and Nephrologist, Renal Unit GRO-B | **WITN4730005** |
| 26 September 2019 | Letter from Dr Alan T Clarke, Consultant Physical and Gastroenterologist, Monkland's | **WITN4730006** |

| | | |
|---|---|---|
| | Hospital, Monkscourt Avenue, Airdrie, ML6 0JS to GRO-B | |
| 31 January 2020 | Medical Note, from University Hospital Monkland's, Monkscourt Avenue, Airdrie, ML6 0JS, entitled "Discharge Letter and Prescription." | **WITN4730007** |
| 14 April 2020 | Medical Note, from University Hospital Monkland's, Monkscourt Avenue, Airdrie, ML6 0JS, entitled "Discharge Letter and Prescription." | **WITN4730008** |
| 04 May 2020 | Medical Certificate of Cause of Death S S Certified by GRO-B | **WITN4730009** |
| 18 Feb 2020 | Letter, from Sally Richards, Scheme Manager, Scottish Infected Blood Support Scheme, National Services Scotland, to Mr S | **WITN4730010** |
| Date as per post park | Letter, from SIBSS Payment Team, Scottish Infected Blood Support Scheme, National Services Scotland, to Mr S Ref.XSB03696. re increase in monthly payments | **WITN4730011** |
| Dated between 26 August 2019 and 24 November 2019 | Email correspondence chain between GRO-B GRO-B and GRO-B | **WITN4730012** |
| 05 November 2020 | Letter from Legal Aspects Team, 2nd Floor Admin Building, Gartnavel Royal Hospital Campus, 1055 Great Western Road, Glasgow, G12 0XH, to Mr S | **WITN4730013** |

| | | |
|---|---|---|
| 10 December 2018 | Application Form, on behalf of S Scottish Infected Blood Support Scheme. | **WITN4730014** |