

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN0150001

Exhibits: Nil

Dated: 12 December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

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

Section 1. Introduction

1. My name is **GRO-B**. My date of birth and address are known to the Inquiry. I am married and have four sons. I intend to speak about my eldest son, **GRO-B: S**. In particular, I will go into detail on the nature of his illness, how that illness has affected him and us, the treatment received and the impact it has had on his and our lives.

Section 2. How Infected

2. My son was infected with Hepatitis C through blood transfusions given at Dundee Royal Infirmary in 1980 and/or Ninewells Hospital in 1983 during surgery.
3. My son has mild to moderate learning difficulties; I have had guardianship over him by court order since **GRO-B** 2007. I deal with all matters in respect of him.
4. My son was born in 1980. As a baby he was unwell; he would cry every time he urinated. We went to the GP who initially said things would improve, but they didn't. When he was about 3-6 months old he was rushed to Dundee Royal Infirmary where he was admitted for a few days and the doctors ran tests.
5. They realised that he had a problem with his ureters and he couldn't urinate properly. His ureters weren't straight, they were floppy, so urine could not flow through properly and was damaging his kidneys.

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6. They operated on him and essentially moved his ureters outside of his body to straighten them, and they attached bags to them so that he could urinate. This was to allow his kidneys to heal properly.
7. After about three years of this, they operated again to reconnect his ureters inside his body. This was at Ninewells Hospital in Dundee. At this point they realised that one of his kidneys was operating at 60% and the other kidney was so damaged it was not working at all. They advised us that he would be able to live his entire life on the one kidney that was working at 60%. I think that at this point they also removed the non-functioning kidney.
8. We know that he was given a blood transfusion but we do not know whether it was at one of these surgeries or at both. This information would be in his medical records.
9. When my son had surgeries as a child, we were never told at the time that he would be having a transfusion. He went in for surgery and we did not ask questions. The reason I am now aware that he must have had a transfusion is that I was given compensation from the government because of his Hepatitis C. The form had to be signed by a consultant to verify the state of his liver.
10. He must have had a blood transfusion because there is no other way he could have contracted the infection. My son did not have any other blood transfusions in the intervening period up to being diagnosed with Hepatitis C. He has never used intravenous drugs and he has no tattoos. We are practising Muslims and he does not drink alcohol. He did not have any more problems with his ureters after the second surgery. He otherwise looked fit and healthy up until 2004.
11. By 2004 my son had developed slight problems; he would occasionally faint and he sometimes got leg cramps, but we did not think it was anything to worry about. In 2004 he went to the GP about his leg cramps; they took his blood pressure, which was really high, and they sent him home and told him to come back next week to get his blood pressure checked again.
12. The following week he went back and his blood pressure was even higher. The GP phoned for an ambulance and he was taken straight to hospital, where they ran tests for about 6-8 hours.
13. We were very worried and concerned. The hospital diagnosed him with kidney failure. We were really distressed and we worried what might be wrong. My son doesn't like hospitals, so I asked the doctors if we could take him home overnight. They said yes, so long as we came back early the next morning.

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14. We were back the next morning by 8am. By 10am the next morning the doctors had him on the operating table to insert a tube into his neck, and by 4pm or 5pm they had attached him to a haemodialysis machine.
15. The tube went into a vein in his neck, and it pumps along to an artery. There are two tubes in the neck; blood is taken out from one tube, goes to the dialysis machine where it is effectively cleaned, and then it goes back into the body by the other tube. It takes 4 hours to do this by machine.
16. His liquid intake had to be very limited. He couldn't urinate, so liquid would stay inside and toxins build up. He was only allowed 1 litre of fluids per day at this time. When he went on the dialysis machine, it would take that liquid out along with the toxins.
17. They explained to us that if someone healthy could donate a kidney to him, then he would be fine. They ran tests on him in preparation for a transplant and blood tests showed he had Hepatitis C genotype 1. This meant a kidney transplant was out of the question, as if he was given a new kidney, the drugs he would need to take as a result would cause his liver to deteriorate a lot quicker. They said his Hepatitis C was pretty bad; he had cirrhosis. The doctors said that they would rather not perform a kidney transplant as he would have a longer life expectancy on dialysis.
18. They diagnosed my son with Hepatitis C within a week of him being admitted to hospital. I was told straight away that he had Hepatitis C. The doctors were nice about it. At the time my other children were at school, so they weren't there; it was myself, my wife and my son's wife.
19. The doctors gave us advice – they said to avoid cuts and not to get my son's blood or fluids on ourselves to make sure that we didn't catch Hepatitis C. The whole family was tested and everyone was negative. I cannot fault the doctors with regard to how I was told about my son's status or with regard to the information they gave us.

Section 3. Other Infections

20. As far as I am aware my son has not contracted any other infections as a result of infected blood.
21. With regard to my son's learning difficulties, I am not aware of these being connected to his transfusion and infection. He was diagnosed with learning difficulties at approximately 6 years old, long after his transfusion. However, he is my only child to have learning difficulties; he has three younger brothers who are all fit and well. One of my other sons had similar problems with his kidneys when he was born, but they did surgery shortly after birth and he was fine.

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22. Two of my other sons are now GPs and the third is a dental surgeon; I sometimes wonder what my eldest son could have been had he not contracted Hepatitis C.

Section 4. Consent

23. As far as I am aware my son was not tested for Hepatitis C nor treated for it without his consent. We only discovered that he had contracted Hepatitis C in 2004 and I am not aware of him being tested for Hepatitis C prior to this date.
24. Since [GRO-B] 2007 I have been my son's legal guardian, so I deal with all matters in respect of his health. It is up to me to say whether he gets given a particular drug or test.

Section 5. Impact

25. For my son, the physical effects of being infected with Hepatitis C have been very severe. We were told when he was a child that his remaining kidney function should be enough to last him for life. By 2004 he had kidney failure and cirrhosis of the liver.
26. Because his liver was so badly damaged by the Hepatitis C, he could not have a kidney transplant as the drugs he would have to take for that would further damage his liver.
27. The doctors told us that it was possible to do a combined liver and kidney transplant but there would be major risks involved. It would be a major operation, up to 17 hours, and two teams of surgeons would be involved. If the new liver didn't work then he would be dead – they would not be able to give him another liver.
28. The Scottish doctors said they would not do this operation, but the consultant was very good and referred us to doctors in England. The English doctors were initially happy to do the combined transplant and sent us to the Royal Free Hospital in London.
29. I wasn't sure what to do, so I told them to decide what they should do. They said that they would only want to do the combined transplant as a last resort, when he was going to die anyway and there was no choice. That way if the operation succeeded, he would get to live, but, as they said, "If he dies in the operating theatre you haven't lost anything". Things worked out OK and I am now glad they did not do the combined transplant and decided to wait.

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30. Because my son could not have a kidney transplant he had to have dialysis. He was on dialysis for ten years in total. When he was first admitted to hospital with kidney failure, they put a tube in his neck and that was how he was attached to the dialysis machine. This was not ideal, so they gave us the options of him having dialysis through a tube inserted in either his peritoneum or his arm.
31. They told us that inserting the tube in the arm can sometimes damage the arm, which might mean they would then need to insert the tube via his leg, but that if that happened there would be a risk of losing his leg. They said the best option was dialysis through a tube inserted into his peritoneum.
32. Peritoneal dialysis could be done at home. I had to order supplies every month; bags of liquid, hand cleaning products, gloves, aprons, waste disposal supplies etc. – all of this would be delivered to me. I had to make sure it was always ordered on time so we never ran out of anything.
33. I would clean the dialysis machine and myself every day, make sure my son was correctly hooked up to the machine, make sure everything was super clean. In the beginning it would take me maybe 1.5 hours to do the preparation each night. By the end I could be finished within twenty minutes.
34. He would spend all night on the machine, he would try to sleep which would not be easy, and then I would unhook him in the morning and dispose of the waste that was produced. Again, this took about the same amount of time as the preparation at night. It was a full-time job, even with three of us to help. But people would say that if you want to give him quality of life, you have to do this.
35. If anything went wrong then we would have to go to the hospital straight away – the middle of the night, during the day, whenever. We would go to hospital for this reason about 2-3 times per month on average. We did peritoneal dialysis for three years.
36. In 2007 my son became very ill with an infection resulting from peritoneal dialysis called peritonitis. He was in hospital for a few days and the infection got worse, so then he was in intensive care. The doctors had basically given up on him; they said there was nothing we could do and they refused to operate. They said he wouldn't make it off the operating table. I told them that if he was going to go, then they had to try, they had to open him up.

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37. They performed surgery for the peritonitis; they took out all the pus and infection and they cleaned him out. He was then in intensive care for a few weeks. He had machines and tubes everywhere. He was on and off the ventilator to make him breathe. He had two nurses, one either side of him, 24/7 to make sure everything was OK. The care was good.
38. Altogether with the peritonitis he was in hospital for about 5-6 months before he came home. He's a big chap, but by the time he was allowed home he was like a skeleton. I used to carry him up the stairs to bed.
39. After the peritonitis he couldn't have peritoneal dialysis anymore. So it was back to the haemodialysis, which had to be done in the hospital. That was 4 times per week for seven years. We would have to get to the hospital for 6am. He would be given his dialysis slot at about 7.30am. He would be on the machine for four hours, and then he might have to wait to be unhooked. It would take up the entire day, and someone would have to be with him the entire time – either myself, my wife or his wife.
40. They had to insert the tube back into his neck at first, and then they operated so that he had a tube inserted into his arm. The needle for dialysis is quite big, so they had to operate to join a vein and artery together to make a big enough blood vessel in his arm for the dialysis needle. This caused his arm to swell up to his shoulder.
41. Haemodialysis would take quite a toll on him. The days he was on dialysis he would be tired and spend the remainder of the day sleeping, so that day was always gone. The day after dialysis he would feel better and he would have that day to do things. But then the following day would be another dialysis day. It had a very big impact on our life. If we needed to go anywhere we had to make arrangements for dialysis.
42. We only went on holiday a couple of times during these seven years. We used to go on holiday more before he became ill. We took him to Spain once whilst he was ill; we went straight from the plane to a hospital for dialysis. Then we had alternate days on dialysis and days on holiday. As soon as we got off the plane back in the UK he went back to the hospital for dialysis again.
43. We also went to Pakistan once; it was the same procedure – we made arrangements with a clinic there and he had dialysis there on alternate days. The difficulty was always the logistics of sorting that out – the hospitals were good, we just had to find a clinic that would take him. My sons would help find somewhere, the clinic would talk to his hospital in the UK, the hospital would send his results over so that the clinic knew what treatment to give.

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44. Even travelling within the UK was difficult. Two of my sons live in Manchester and Leeds, so if we went to visit them there we would have to find a hospital, make an appointment etc. and arrange dialysis.
45. During this ten-year period my son tried all the drugs available for Hepatitis C. None of them worked. In 2014 the doctors told us to be patient as new drugs would come to the market; they told us there was one coming soon that could be a miracle drug. From this point the doctors said he shouldn't try any new drugs for the Hepatitis C as they might make subsequent drugs less effective.
46. So we waited for the miracle drug to come to market and my son remained on haemodialysis. We were concerned at how long he had been on it; people don't tend to last that long on dialysis. He had been on it for ten years, he could have had a heart attack or something else happen.
47. In or around 2015 the miracle drug we had been waiting for came out. We travelled up to Dundee from Manchester. The consultant called me and said that they would like to try the new drug on my son, but that I would need to give him a kidney first. This was because if they gave him the drug when he was on dialysis, the machine would just dialyse the drug out. So he needed to have a working kidney first.
48. They started the process of checking me and my son out for the transplant; it took about 7 months altogether, then I was able to give him my kidney and it was working fine. My son and I spent about 2 weeks in hospital after the transplant, then we were allowed home. A week later he was put on a month-long course of tablets, one per day, called Harvoni.
49. Within two weeks of him being on this new drug, the Hepatitis C had cleared, but he took the full month of tablets. He didn't really have any side effects on this new drug. Although the hepatitis has cleared he still has regular check ups every 6 months.
50. After the kidney transplant, they had to operate on his arm to separate the artery and vein that they had connected to make a fistula for haemodialysis. They also had to remove tissue so the swelling would go down. It took a year after that for the swelling to reduce.

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51. My son is now fine and healthy; he has a working kidney and no Hepatitis C, although he has to take drugs for the rest of his life to stop the kidney rejecting. But his liver remains damaged. The doctors say there is nothing they can do if it deteriorates any further. His liver shouldn't get any worse, but the damage is already done and it can't be reversed; he has cirrhosis and that will be permanent. His liver might improve with time, it might not. We will have to wait and see what the liver damage means for the rest of his life.
52. Arteries around his body, including his heart and brain, will be damaged from years of haemodialysis, resulting in increased risk of heart attacks and strokes.
53. The liver damage from the Hepatitis C has changed his life. He and his wife have not had children because of it. They could have had children, but they didn't. Now because he has had a kidney transplant he cannot be given drugs to get his body functioning properly, so they cannot have children. His brothers are all happily married with kids; it is sad. But this is the hand we were dealt.
54. Because of his learning difficulties, my son has never been able to work and he would not have returned to education. We have been affected financially because of his illness; although treatments are free in Scotland, including prescriptions, we have incurred costs in hotels and travel, particularly when we went down to London to see about the combined transplant at the Royal Free Hospital.
55. My son's illness has also had a big impact on the rest of our family. His brothers were at school when he first got ill; it had a big emotional impact on them. When he had peritonitis, one of his brothers failed his exams. He had been studying all that time and had to re-sit the exam. His brothers help take care of him still; he goes to their houses, they go on holidays with him.
56. As my other sons are all in the medical and dental professions, they have been very involved with his care. They ask questions for us and they help me with reading and writing documents as I struggle with that.
57. It has also had a big impact upon my son's wife. Their marriage was arranged in 2001 before my son became ill; we didn't realise he had Hepatitis C. We wanted him to get married because we would not be here forever and we wanted him to have a companion.

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58. My son loves her and she cares for him, but she has taken on a lot of the burden of looking after him. When my son used to have dialysis at home, she would help with that, and she would go to haemodialysis at the hospital with him. It is stressful. When she got married she did not expect that this would be the case; she has lived with this for that amount of time. She had wanted to work and earn a living, but she hasn't been able to because of his illness.
59. My wife has suffered a lot too. Her health is very poorly now. She has spent years being in and out of hospitals worrying about our son, worrying how long he would live. We have stayed in hospitals overnight a lot. There has been a lot of anxiety. My wife has been worn down by this; she is old and frail.
60. It has affected my ability to work; I work hard to provide a decent life for my family and to do the best I can. Before my son got ill I ran my own business; I used to own several shops and would work 12 hours a day, 7 days a week. But because of the going to hospitals and appointments and caring for my son everyday, I had to give my business up and begin working for other people.
61. During that ten-year period when he was ill, I would have to stop work whenever he got ill. Sometimes I would take a few days off work, sometimes I would need a week off work. On average I would be able to work approximately 20-30 hours per week when he was stable. My employers were very understanding. I am still only able to work about 20-30 hours per week.
62. I do not have any health implications from having donated my kidney; the doctors say one kidney is enough to survive. I don't experience any pain or difficulties, I just need to make sure I live a healthier lifestyle and don't put on too much weight.
63. When my son is ill, I have to care for him. It is very full caring – I will have to wipe his bottom, clean and tidy, put sheets on the floor for waste in case he can't get to the toilet, wash him etc. When he is ill he will not let me out of his sight.
64. We told our family, family friends and professionals about my son's Hepatitis C. We did not tell anyone else though. All of our family and friends have been great; they didn't treat him any differently. The only difference was that because our culture is very kissy and cuddly, we told our son to only kiss people on the cheek.

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Section 6. Treatment/Care/Support

65. Once my son was diagnosed with Hepatitis C he did not face difficulties in obtaining treatment, care or support. The doctors and nurses just had to take extra precautions, they knew to sterilise things etc. There were some needle-stick injuries but the consultant told them to be careful. There were no issues. I cannot fault the medical profession for their treatment of my son with regard to his Hepatitis C. Everyone was very nice and caring, I have nothing bad to say about them.
66. Neither my family nor myself were offered any counselling or psychology services when my son was diagnosed with Hepatitis C. We didn't ask for any such service either; culturally, counselling is an alien thing to us and we would not have wanted it.

Section 7. Financial Assistance

67. My son received assistance from the Skipton Fund and now SIBSS. We found out about the Skipton Fund from our solicitor, who we had engaged for litigation against the hospital.
68. We applied to the Skipton Fund through the consultant; he filled in the form. Initially we received £11,000 a year in annual payments. We then got two lump sum payments totalling approximately £50,000. The second payment was for cirrhosis of the liver. After that, we then got another £20,000 on top; I think this is when Scotland increased the amount. These lump sum payments were on top of the annual payments.
69. As of now, my son receives £27,000 per year. His last payment from the Skipton Fund was £14,000 per year. My understanding is that his payments carry on for the rest of his life, and that when he passes, his wife will get something.
70. It was fairly straightforward to get the annual payments and lump sum payments from the Skipton Fund, but we were told that in order to get money from the Skipton Fund, we had to sign away our rights to sue the government. The other support though – the grants available – were not much help.
71. For example, we would like to move to Manchester, but we will need a mortgage and it is difficult to get. My son would not be able to get a mortgage for his own house. His condition would affect insurance policies, mortgage protection policies. The premiums would be much higher.

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72. In terms of the financial assistance available, I feel that the Irish government gave people a decent amount. The British government wasn't decent enough. My family are lucky to be reasonably well off – we aren't poor. We are grateful for what we have. My son gets a reasonable amount of money, but even then he cannot live on his own on that amount.
73. If the government gave him decent compensation he could buy a decent house and live comfortably with his wife. If this had been something that had happened to him on his own, then fine – but if the government knew about it and didn't do anything about it, if they lied – then they paid him a pittance. The Scottish government have been generous.
74. The help my son gets financially does not make up for it. Even if we got a big cheque it wouldn't make a difference; it might just make him more comfortable now.

Section 8. Other Issues

75. I feel that obviously doctors knew what had happened – they had records of people who were infected with Hepatitis C by blood transfusions. They could have called people and got them checked, but they didn't.
76. We went to a specialist solicitor in Edinburgh to sue the hospital that had treated my son for his kidney issues as a child, because we did not think they should have discharged him when they knew that he only had one kidney functioning at 60%. The hospital let us down; they told us the kidney would last a lifetime and it didn't – there should have been follow-up care. I think that if he had been looked after properly, if the Hepatitis C had been picked up earlier, then maybe he would have had more dialysis-free years.
77. We got legal aid for the action, which was simple enough, and it was granted very quickly as my son was on benefits and had no income, so it was a straightforward application. In the end the hospital settled with us for £37,000. They calculated that with earlier intervention, he would have had 5 more years before he would have needed dialysis. I feel that was wrong; a different method of calculation indicated that he could have had 15-20 more years dialysis-free. I think the settlement amount was very small considering it was meant to reflect 5 years of being dialysis-free.
78. The case took 5-6 years from the beginning through to settlement. It was a very stressful time. I struggle with reading and writing, so my children do a lot of the work for me.

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Statement of Truth

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

Signed

GRO-B

Dated

12/12/2018