

# ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0451001

Exhibits: Nil

Dated: 20/11/19

## 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 10 June 2019.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1947 and my address is known to the Inquiry. I am married and I live with my husband, GRO-B. We have two daughters and four grandchildren. We are both retired.
2. I received blood transfusions following a serious car crash in 1967, and for major abdominal surgeries in 1975 and 1976. I went on to develop hepatitis C. I will discuss the impact that this has had on my life.

**Section 2. How Infected**

1967 – road traffic accident

3. I was involved in a car crash between [GRO-B] and [GRO-B] on [GRO-B] 1967, when I was 20 years old. I was a passenger in the car.
4. I was taken to the [GRO-B] a [GRO-B] where I remained for four months with serious injuries.
5. I had two broken legs and multiple facial cuts and was in a very bad state. They had me in traction and in a total body plaster at different points.
6. I ended up having seven or nine operations in total, because they kept on making mistakes with fixing my legs.
7. I was given several blood transfusions during this four-month period. I do remember seeing pouches of blood and drips going into me.
8. They didn't say anything to me beforehand about giving me blood.

1975 and 1976 – major operations

9. In 1975 I was admitted for an emergency operation at [GRO-B] [GRO-B] I was at death's door. Although I did have lengthy discussions with the surgeons about the nature of the operation, I do not remember blood transfusions being discussed. I was in too weak a state to notice if I was given a transfusion straight after the surgery.
10. I do remember, however, that some days later I was given blood, because I was found to be very anaemic and was very weak. According to the theatre nurse, I had lost a great deal of blood during the operation. I did not question these transfusions.

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11. I do remember that, after these transfusions, I suddenly took a turn for the worse, with all the symptoms of a violent infection. I suspect this is when the hep C virus took over my body: I lost the initial battle with it, and the virus became chronic.
12. I was readmitted in 1976 for a follow-up operation. Once again I was given blood, without any prior discussion. It is only in retrospect that I have realized that, in this 1975-1976 period, contaminated blood products were subject to debate in government circles (David Owen) and in the wider media (World in Action, *'Blood Money'* December 1975).
13. After this operation, I was in the best health I had ever been in, because of course I had been treated for what had been undermining my health in quite a big way.
14. It was 25 years later, I think, that signs of what would later be diagnosed as hep C became clearly apparent. I was well: very active, full of energy, doing lots of things – and then, gradually, things changed.

### Diagnosis

15. It was around 2001 when I started to feel unwell. I put it down to doing too many things. The main symptom was that I felt totally exhausted.
16. I used to have seven allotments and grow my own fruit and vegetables. All of a sudden, I couldn't walk from here to the corner. I would become out of breath and completely run out of puff.
17. After a time, I went to the doctor and he said, "Every person who walks through my door these days complains of lack of energy". I told him that I knew this was different: normally, you sleep, you rest, and you wake up refreshed. This kind of tiredness was endless though. I was sent for blood tests.

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18. We went abroad for a week or so and, caught up in other events at home, I did not follow up on the tests until several months later. The surgery did not contact me in this time.
19. When I eventually booked an appointment, my usual doctor was away. The GP said, "Oh my God, GRO-B" when I saw him. He showed me the test results and everything that came up, almost all the measurements, were flashing red.
20. He said, "We get results like this from alcoholics", and told me to give up whatever I was drinking. I had been drinking a small tin of lager with lunch and the occasional whisky on an evening. Not a serious drinker!
21. When my own doctor came back, I went to see him. He told me it could be one of three diseases: hep C, haemochromatosis, and something to do with the gall bladder, I think.
22. My daughter is an acupuncturist and was looking up the diseases for me. She said, "Oh, that's terrible, I hope it's not hep C, that's a tough one", whereas she felt that she could have helped me with the other diseases using acupuncture.
23. GRO-B and I started doing a lot of self-educating at this point, and it was not pleasant reading. Everywhere I looked, hep C was referred to as the 'silent killer'.

### Information provided and its adequacy

24. I was referred to Warwick Hospital for the defining test, which came back mid-2003. It was hepatitis C. I had genotype 1, which was the most difficult to treat. At Warwick Hospital I saw a Dr Shearman, who had a special interest in liver problems.
25. Initially I was asked if I injected drugs or had had multiple sexual partners (with my husband sitting next to me). This was my first indication of the 'pariah' status of hep C. When discussing treatment, I remember he said,

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"You can come to me in 10 years' time and have the treatment then". I said, "You mean I have 10 years?"

26. I think I might have asked about the risks of hep C at this point, but it was all very shocking.

27. There wasn't much information offered at this point, not much explanation, it was factual.

28. I had already read about Interferon and Ribavirin, the treatments then available for hep C. I thought, no way, I don't want the Interferon in particular.

29. If I hadn't done research myself I probably would have embarked on the treatment, and I would probably not have survived it.

30. Dr Shearman told me that Birmingham was doing trials, and referred me to Professor Mutimer at Queen Elizabeth Hospital, Birmingham. Professor Mutimer looked after me from 2003 – 2016.

### **Section 3. Other Infections**

31. Hepatitis C was the only disease I was infected with, although I have suffered many health consequences from it and as a result of the treatment.

### **Section 4. Consent**

32. Professor Mutimer asked me at one point if I would be willing to take part in some research by giving blood samples so they could test how HCV developed in those infected.

33. I thought that I could help by taking part in this survey. This was during 2015 – 2016.



**Section 5. Impact**

**Mental effects**

34. When hepatitis C was confirmed, it was a great shock. It was a shock when I had been reading about the disease prior to diagnosis, but there was always the hope that I would not have *that* diagnosis. It was very traumatic. I thought, *This is it, it's all over*. It's like hearing you've got cancer and all of a sudden you've only got a few months to live.
35. It is a 'silent killer'. It had been working for decades silently and insidiously. This was what I knew from the reading I had been doing. By the time you know about it, the irreversible damage has been done.
36. I was actually at a good time in my life. Having had children young, they were now grown up and the grandchildren were a central part of my life (at that moment I had three under ten years old). I was looking forward to new challenges in my life and to enjoying my golden years as their grandmother.
37. I've always been an upbeat person. I am the one that people turn to for help or advice. I have never had a panic attack in my life. I now have panic attacks, 'physical' panic attacks.
38. I have become agoraphobic. I go out sometimes but I avoid venturing out too far. I became generally afraid. I lost trust (especially in the medical profession). I lost control over my body, my life, my mental and psychological state, and had no help from anywhere. There was no light at the end of the tunnel. The amount of fear and desperation you feel when there is no hope can be crushing. I had to put all my faith and trust onto my acupuncture and my herbs and hope that this would see me through until a tolerable treatment became available.

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39. I have never before had a nervous breakdown. I now have meltdowns regularly. It has affected everything. I have become a different person, it is safe to say. I hope that I will improve mentally, but it is a struggle.
40. I don't know how to describe the emotional things. But, without looking to sound melodramatic or excessive, it's been bad. I've had big bouts of depression. I think that now I probably have low to mid-grade chronic depression. I don't want antidepressants. The answer is always, drugs, drugs, drugs, and I don't want drugs anymore.
41. There are a lot of emotional upheavals that you have to deal with and nobody comes to offer you any professional help.
42. My greatest grief is that I am a grandmother and I have not had the energy to participate fully in the life and development of my grandchildren. In the 2000s, soon after my diagnosis, the husband of my younger daughter developed cancer and eventually died. While I tried my best to help them all – a young family with two infants – I could have done much more as a woman in good health.

### Physical effects

43. Physically, the fatigue has been the worst thing. Anybody who hasn't felt it, doesn't know. It's a different kind of exhaustion that is distinct from normal exhaustion. It is endless, merciless, relentless.
44. I have other things like muscle pains and feeling generally ill. Every day. And with a cirrhotic liver, I live with the fear of my liver gradually ceasing to function; I am tested every six months for liver cancer.
45. I have experienced a lot of pain in my life – with my other hospital admissions. Sometimes I'd think: if I could choose between acute pain and this exhaustion, which one would I choose? And I could not decide. (Now, post-treatment, I have both chronic pain *and* exhaustion!).

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46. My eldest daughter lives abroad and has two kids there. We would take it in turns to visit each other every three months or so. But I began having to pull out of travelling, which limited my contact with them.
47. I couldn't tell the grandchildren, obviously, because they wouldn't have understood. It really deprived me of the greatest delight in my life that I was looking forward to.
48. My other daughter, here in the UK, had just had a baby, before my diagnosis. I couldn't even lift the baby. This was at the point where I didn't realise I had hep C.
49. For over 20 years it has been torture for me, one way or another, physical and mental torture.

### Further medical complications

50. Everything in my health has deteriorated as a result of being infected with hepatitis C.
51. I have digestive problems and have lost several stone in weight.
52. I have brain fogginess at times. I have had to give up driving.
53. With regard to my overall health, it feels that almost every organ of my body has something malfunctioning. Although I've not been to the doctor to receive a specific diagnosis for all these other problems.
54. I am an invalid now, really. It shames me to say it. My husband does everything. This makes me mad at times. I try to adjust to my 'fate'. But the last 20 years of my life have been completely stolen from me. Why?
55. When I look forward, I can only see more of the same, and then the horrors of a painful death at the end. I wish that it hadn't happened. This is what is so difficult to deal with... There is no reason for it to have



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happened. It was not necessary. It was not unavoidable. Was it? There is a lot of anger to deal with.

### Treatments and their effects

56. If I hadn't read about the Interferon and Ribavirin, then I probably would have taken it. Thank God I didn't, because I am not robust enough for that. I would not have managed.
57. Professor Mutimer and I both agreed that I wouldn't have coped with the treatment and he allowed me to wait for new advances in treatment. But it was a long, anxious wait, of more than ten years.
58. I went on to the hospital waiting list and hoped that treatments would come along. We thought that, in terms of new treatments, Birmingham was the best place to be: it had a specialist liver unit and was at the forefront of research.
59. They were scanning my liver every six months. I refused a liver biopsy and had a fibroscan instead. It found that I am cirrhotic.
60. I was already doing acupuncture for general health maintenance. We found out about someone in London who was working wonders for hep C. I transferred my acupuncture to this clinic and I've been visiting it every three or four weeks in London, for the past 14 years. I also take Chinese herbs.
61. My viral load reduced from the tens of million down to some 3,000 – without any other forms of treatment. This was over roughly a 10-year period.
62. It took some time for any change to take place through acupuncture, but then the viral load started reducing steadily.
63. On 24 November 2015 I started on a course of Harvoni. I took one pill a day for three months.

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64. It was fine, it didn't give me anything noticeable – no nausea or sickness. I did feel more tired though, I stayed in bed most of the time.
65. I did lose a lot of my hair, and I lost a lot of weight.
66. I was very pleasantly surprised that my viral load was undetectable after this treatment.
67. However, I noticed, in the months following the treatment, that I started ageing very fast.
68. My heart is worse – I run out of puff and am breathless more than I used to be.
69. I have unexplained pelvic pain. It feels like I am being cut inside with razor blades, or burning at times.
70. The long and the short of it is, I'm now in daily, constant, agonising pain.
71. I can only think that these other things are related to the Harvoni because they've appeared in a cluster, within months of the treatment. They can't all be due to the natural ageing process. If that is the case, what can one look forward to? Will I ever reclaim my health and my life again?

### Difficulties or obstacles in access to treatment

72. In September 2014, Dr Holt at the Queen Elizabeth told me that I faced a very difficult future unless I went onto a treatment as a matter of urgency. (At that point Harvoni had not yet been approved as a treatment option.) I continued with my acupuncture.
73. In March 2015, I was told that NICE approval for new treatments would hopefully be granted in May/June and that, given my case file, I would be a top priority for this. I wrote to Dr Holt in May to ask if I could be

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offered this treatment as soon as possible given that I was in such poor health.

74. I was given the drug in November 2015.

75. I haven't had any problems with the dentist. My dentist has been very nice about things.

### Effects on private, family and social life

76. I have kept my condition hidden from almost everyone. Peoples' attitudes towards you change when they know you are seriously ill. They don't realise it, but it does. Plus, this particular illness has the stigma of contamination, of you being a danger to people.

77. We kept on turning down invitations and in the end, people stop asking you.

78. We used to have a fun and interesting social life. We don't engage much with the outside world anymore.

79. Being sociable is not easy physically, let alone psychologically. Even though I don't have the virus anymore.

80. I used to cook a lot. This is one of the things that I loved doing, everyone loved me doing it, and now I can't do it anymore. Now my husband must try and do the cooking because I am meant to be eating every two or three hours since my liver can no longer store protein effectively.

81. I had my beautiful allotment, you can imagine how passionate I was about this. It was my paradise. I had to give it up and that has really cost me a lot.

82. My husband would often travel in the GRO-B for work, and I would try to join him when I could. This is now out of the question for him and people have now stopped sending him invitations.

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83. GRO-B couldn't be more supportive. I don't know what I would have done without him.

84. He is very worried all the time, very preoccupied. There is an enormous burden on him. I wouldn't say that his character has changed, but of course he is anxious about things. Life used to be benign – we were lucky.

85. Families change. I'm lucky that we were always a strong, close and loving family, but it has had its strains. I was the hub around which the family gathered: I'm the grandmother, the mother, the wife. And that's gone now. It's almost like having to find a new identity for everybody.

86. The dynamic of the family has changed and it has affected everyone. There was no need for any of this. Why did it have to happen? In cold blood, they chose to go with a policy that spelled death. It is very hard to come to terms with this.

### Stigma

87. I have felt stigmatised and that is why I have kept it a secret. I have isolated myself and alienated our friends.

88. You are made to feel – from the first questions in hospital – that you have a 'dirty' disease that only drug users and the sexually promiscuous catch.

89. I have felt like a pariah, and like a walking bomb who could infect others. Psychologically, you do feel like a leper.

### Effects on education, work and finance

90. With my formal education behind me, I was now taking classes in different things. Upholstery, for example. There were lots of things that I was interested in, and was looking forward to, but was unable to pursue because of my infection.

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91. Everywhere you see elements of what could have been and you live with that every day. A constant reminder of endless losses. Our unfinished – and now crumbling – house is like a metaphor for our lives. I keep hoping that one day, somehow, I will finish upholstering the chairs.

92. I had reluctantly given up my job, teaching private language classes, because I was so tired. I thought at the time that this was just because I was doing too much.

93. GRO-B took early retirement because of my illness. He was a professor at the university but retired seven years ago.

94. I've spent a lot of money on alternative treatments. Every time we go to London for the acupuncture, for example, we incur significant expenses.

### **Section 6. Treatment/Care/Support**

95. I have not encountered any obstacles, but I haven't encountered much help either. No support system was offered at all, really.

96. NHS care was nothing special. It's been the minimum, a six-monthly hospital check (a scan and blood tests). But I always found Professor Mutimer supportive.

97. No counselling or psychological support was offered, no. Of course not, by whom?

98. We didn't even think that this Inquiry was going to happen. One loses trust and faith in justice among so many other things.

### **Section 7. Financial Assistance**

99. Professor Mutimer was the one who first told me financial assistance was available. He told me I could go to the Skipton Fund.



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100. I received £20,000 lump sum payment around 2006 and the £50,000, part two payment for my cirrhotic liver around 2010.
101. I did not have to sign a waiver in order to obtain these payments.
102. I now receive a monthly payment of £1,500 per month. This is set to increase.
103. Whatever the process was, it was easy. I have no problems or complaints about the Skipton Fund.
104. If I was younger and had had to give up my career and had small children, that money wouldn't have been adequate to cover expenses. As it is, I put much of it aside so that I can have, hopefully, dignified and dedicated health care in my final months and years. It is, very literally, blood money.

### **Section 8. Other Issues**

105. I have not taken part in any campaigning in relation to this matter, nor been involved in any previous litigation. I have not searched for my hospital records ( GRO-B 1976-76).
106. I remarked in a letter that I wrote to Birmingham Hospital in 2015 before treatment, that I had been reading the Penrose Inquiry Report. It stated that, according to the NHS, every effort had been made to contact those who had received blood transfusions before 1991.
107. I advanced my concern that I had not been contacted. My National Health Number is still the same, so why was I not told that I might be in this high-risk category? I was in robust health between 1991 – 1995 when this look-back was being conducted. Had I found out back then that I had hep C, I could have made lifestyle changes or even had the energy to take on an aggressive treatment.

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108. I've always had so much trust in doctors and the health profession. I put my life in their hands. I trusted.

109. This trust has been betrayed and is now gone.

### **Statement of Truth**

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

Signed

GRO-B

Dated

20/11/19.