Witness Name: GRO-B
Statement No: WITN0646001
Exhibits: **WITN0646002 - 004**
Dated: 01 August 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 04 April 2019.

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

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1963 and I live near Bristol. I am married, have three children and two granddaughters and live at home with my husband of 35 years, and my daughter. I work part time as a Health Centre receptionist and have worked for the NHS for 17 years.

2. I intend to speak about my mother, GRO-B: M s infection with hepatitis C, (HCV) which she acquired as a result of a blood transfusion. In particular, I will discuss the nature of her illness, how the

illness affected her, the treatment she received and the impact it had on her and our lives together.

3. I am not legally represented and am content for the inquiry investigators to assist me with writing my statement.

4. Regarding anonymity, I have discussed this with my family and we have decided to ask for anonymity. My mum was a very private person and I will respect this. Additionally, my children work in the public sector and I really do not want any backlash for them.

Section 2. How Affected

5. I was the only child of my parents, M and GRO-B My mother was born on the GRO-B 1933. She died on GRO-B GRO-B 2018, just before her 85th birthday.

6. She was the head chef for GRO-B. My father had been in the RAF and was later an Engineer for GRO-B, until he took a medical redundancy aged 58, following two heart attacks. He passed away in the GRO-B of 2007.

7. In December 1977, my mum went to GRO-B Hospital for a routine gynaecological appointment, as she was suffering from menorrhagia. The consultant she saw, Mr GRO-B expressed concern that she was very pale. After blood tests showed that she had a haemoglobin count of 7.2, he recommended that she be admitted as an emergency inpatient.

8. After protestations, she was admitted for further testing and with a plan to transfuse her. She was admitted for seven to eight days. I recall that this was because they had trouble with stocks of her blood group, which was O negative, and as such she had to wait for the hospital to receive supplies. At the same time, I recall she also had a bone

marrow test done; I think they thought she had some kind of blood cancer or leukaemia.

9. I produce as my exhibit, a Request for Blood Transfusion from Bristol Health District which lists the blood bags of the four units of blood Mum received between the 6th and 7th December 1977. Bag No's J8109-16912- 59449-16910. **WITN0646002** refs.

10. At no point prior to her transfusion were the risks of it explained to my mum. Had she known that the blood was infected she would not have consented to the transfusion. It's about having an informed choice. Our expectations would be that the blood was fit for purpose.

11. As a result of the transfusion, my mother was infected with Hepatitis C, genotype 1a/1b.

12. We found out about Mum's infection 25 years later, in September 2002. She had been suffering with a cough for a few weeks and was very tired. I went with her to her GP at GRO-B, who referred her for a chest X-Ray and blood tests. The X-Ray came back clear, but she was sent for further blood tests. When the results came in, Mum was called for an emergency appointment. I again went with her. (Dad did not like going to appointments, particularly after his heart issues.)

13. An overview of this appointment and its follow up was sent in a letter to a Consultant Gastroenterologist from the GP and shows that Mum first tested positive for HCV on 25th September 2002. I exhibit this as **WITN0646003**.

14. She saw a locum GP, who she had not met before. The locum asked if Mum had ever had a transfusion. If she had looked through Mum's notes, she would have known about the transfusion. She also asked Mum if she had ever shared dirty needles or had promiscuous sex.

Mum was not happy that she had been asked those questions. She had only ever been with my father.

15. It was at this appointment that we were told about Mum's Hepatitis infection. We had never heard of it before and didn't know what it was. The way it was explained made us think that Mum only had a few months to live. It destroyed Mum and she gave up on life for a time.

16. At the time there wasn't a lot of help, information or counselling from anyone on how to manage the infection and understand the virus. We were told that hepatitis C affects the liver, but we were not given any information about the risk of passing on the infection to others. She was only advised not to share toothbrushes and to be careful if she had an open wound.

17. That ten-minute consultation was absolutely life changing. We left the surgery in a very low mood. Mum turned to me and said, 'well that's it then GRO-B I've only got a few months'. She was so angry. When we got home she told my dad that she had bad news and told him what it was. However, he didn't know what her diagnosis meant, and just went inside and had a brandy.

18. Not long after getting this diagnosis, I applied for Mum's medical records and found the records relating to her transfusion in 1977. I have since applied for, and received all of Mum's medical notes, from 1972 to her death in 2018.

19. We had to wait months for a further appointment at the Bristol Royal Infirmary for further liver scans, blood tests and to just find out information about the infection.

Section 3. Other Infections

20. I do not believe my mother was infected with anything other than hepatitis C as a result of her blood transfusion. We were not told of any other infections and I would imagine they did tests.

Section 4. Consent

21. My mother did not consent to be treated or tested for the purposes of research and I have no knowledge as to whether this happened or not.

Section 5. Impact

22. Mum received the contaminated blood in GRO-B 1977; I was about to turn 14 years old. I remember Mum always being tired. She started work very early in the morning and would be home by around 2:30pm. As soon as she returned, she would fall asleep. She was often fatigued and became very temperamental.

23. Whenever we went to the cinema, Mum would fall asleep during the film. I just kind of got used to her tiredness, you do when you're a child. As I got older, I wasn't there as much so couldn't keep track of her health and how she was feeling.

24. Once she was diagnosed, Mum continued to have sleep issues. She never slept at night and thus would be exhausted in the day and therefore unable to carry out her daily life.

25. Mum and Dad always ate well, and Mum rarely touched alcohol. After her diagnosis she always felt like she had to explain why she wasn't drinking. There was a stigma attached to her diagnosis and not being able to have a drink. Her cirrhosis was not caused by drink but by the

infection. She felt the need to explain this; she hated the thought of people thinking she was an alcoholic.

26. Watching Mum come to terms with her disease was emotionally and physically hard. Her mood would change daily due to pain and she would frequently feel depressed and fatigued. At times she didn't want to leave the house and would pull the blinds down and sit and become reclusive. This was exacerbated after my dad's death in 2007, though I'm glad he didn't have to see what happened to her.

27. The hepatitis had affected their marriage and although they had already been sleeping in separate beds, I think they spent even less time together after her diagnosis. Dad was tested but he was considered fairly low risk.

28. Mum's worsening depression caused him to go out drinking and gambling. He had always liked to go for a drink and down to the bookies but it definitely got worse after her diagnosis. As she became progressively reclusive, he would spend more and more time gambling, he would also turn up at my house and I would find him watching the racing on television. On these occasions I knew that things must have been bad with mum.

29. They only went on one holiday between being diagnosed and my dad's death. Mum regretted not spending more time making memories with her husband whilst they had the chance.

30. One of the letters I received with Mums medical file is from her Consultant Hepatologist, Dr Fiona Gordon to her GP Exhibit **WITN0646004 refs**. In it, she mentions that Mum 'had developed a vasculitic type rash on her legs in 1995, (Photograph in BRI case notes) which may represent Hepatitis C related Cryoglobulinemia'

31. On reading this letter it appears that Dr Fiona Gordon is making this statement with hindsight. However, the rash could have been an early indication that Mum had hepatitis, as far as I know the medical staff at the time did not carry out any tests for hepatitis. Was this an opportunity missed for early diagnosis? I suppose we will never know.

32. There was a delay between diagnosis and the beginning of treatment. Even so, Mum's liver was monitored every six months and we were told she had a fatty liver. She lived for the next scan, always hoping for 'no significant changes'. I have since read that she had fibrosis of five to six out of six. Her complexion and eyes would change regularly.

33. Mum began a 48-week course of pegylated Interferon and Ribavirin in 2003. The time she spent on treatment was horrendous. She lost two and a half stone in weight, developed skin rashes, was severely fatigued and suffered badly with depression.

34. She would inject herself on a Thursday, would be alright on the Friday and then spend the weekend in bed with fatigue, flu-like symptoms and shortness of breath. She became anaemic and would occasionally vomit and have diarrhoea. She also developed varices on her throat. It was a continuous cycle.

35. There were more bad days than good with the treatment. She had rashes and dry skin, itchy skin; She tried numerous creams from the GP, which didn't really work.

36. Whenever she went for a consultation, we had to wait in the same waiting room as those who appeared to be drug addicts and those who for example had chosen a different lifestyle to my mother. She was often the oldest person in the waiting room.

37. We didn't expect any special treatment and we didn't get it. The nursing staff and consultant were lovely but it was very much a conveyor belt system.

38. Whilst on the treatment, her mobility suffered, she developed peripheral neuropathy in her feet and legs, which went up to her knees. She couldn't feel her lower legs or feet; this meant she had numerous falls.

39. On one occasion, she broke her wrist after falling and required surgery and a metal plate to be inserted in to her wrist. On another occasion, she fell whilst getting up from a chair and broke her ankle and ribs, which meant weeks of immobility. There was plenty of help offered from District Nurses, Physiotherapists, Doctors and of course, the family.

40. Consequently, she had to walk with a frame. She became less and less confident in leaving the house alone, except to the hairdressers, which she would go to twice a week.

41. Her attitude towards the family changed; one day she would be lovely and the next, absolutely awful. She had always been young at heart and would rather be with young people rather than old. However, she couldn't stand to be around the children at times.

42. Additionally and as a result of the infection, she suffered with persistent tooth and gum issues. She has a lot of dental work, fillings and extractions. The dental practice was aware of her infection and treated her well, her appointments were either the last in the morning or last in the evening.

43. We were not warned of any of the side effects prior to starting treatment.

44. We were heartbroken to learn in 2004 that the treatment had not worked to clear the infection, but we tried to continue life as normal. Mum's depression worsened still; we had gone to the hospital with high expectations as she had begun to feel slightly better so finding out it hadn't worked left us very disappointed.

45. She would always put on a front to doctors and would never admit to being depressed, despite being prescribed several different antidepressants. She would take them for a while and then give up. As such, they never really worked.

46. In 2016, Mum was offered a new treatment, her notes say it was, Viekirax, Ribarvarin and Exviera, It had been mentioned to us the year before, but it had not been approved by NICE. When it was approved by NICE, Mum was sure she wouldn't be offered it, as she thought she was too old. However, she was offered it, and began treatment on 29th January 2016.

47. She continued to suffer side effects that were similar to those she had experienced on the Interferon, but much less prominently. She lost weight and had a loss of appetite and was very fatigued. So much so, she ended up in bed again. She also had to have her bloods taken every week at the BRI. Mum was very stoic, she wanted to stay at home and not bother people, therefore I can't be sure how much she actually suffered in private.

48. In April 2016, we were delighted to learn that 39 years after her initial infection, Mum had been cleared of the virus, aged 82. However, the following year after receiving the all clear, we received yet more devastating news.

49. In September 2017, she went for her routine six-monthly scan on her liver. Following this, she was referred for an MRI and a CT scan. She was told that they had noticed something and was asked to see her

liver consultant. She had been suffering with tightness in her chest and back and had lost more weight.

50. The Consultant put an image up of Mum's pancreas and explained that Mum had an inoperable tumour the size of a ten-pence piece. She was not offered chemotherapy or radiotherapy and was just told to go away and live her life, there was nothing they could do.

51. Even in the face of this diagnosis, Mum was amazing. She knew she had cancer but for eight months and even though she felt terrible, she kept going. We tried to make sure she didn't miss out on anything and would go for afternoons out together and had everyone round and together at Christmas.

52. In May 2018, Mum took a turn for the worse. We were due to go out but she called and said she had been sick all night. It turned out that she had a blockage in her bowel and was vomiting its contents as a result. She was admitted to hospital for six weeks and had to have a nasogastric tube (NG tube) fitted. She had gastroparesis and hyponatraemia. On one occasion when she was having a vomiting episode, a nurse came in, saw what was happening, and just walked out of the room again. We were left to care for her alone.

53. She was eventually discharged, but didn't want to go to a hospice, though it was clear she needed palliative care. It took us a week or so to get everything in place: we had a bed installed downstairs, commodes and the District Nurses were on board to provide assistance.

54. Over time, the tumour grew and the cancer moved to her bowel and lungs. Her stomach was huge with the tumour and caused her to become herniated. She almost looked pregnant with her large stomach, despite having lost a lot of weight.

55. She was discharged with a syringe driver, through which she was administered Metoclopramide, in addition to Levomepromazine, which was a subcutaneous injection. It meant she wasn't in pain, which was the main thing. She spent almost three months in bed: the doctors were amazed – it seemed like although her body had given up, her mind wasn't ready to go.

56. After a change in her medication, she took a turn again and struggled to keep her eyes open. We were also warned that she would lose her ability to speak. It was particularly difficult when that happened. However, on a few occasions, she had episodes of lucidity and would speak to each family member, as if she was saying goodbye. Her final words to me were 'you're my only child' She lived for another 10-11 days, but never regained consciousness.

57. It almost felt like a relief when she eventually died on the GRO-B GRO-B 2018. It would have been difficult for the family to continue caring for her and it wasn't fair on her either. It didn't feel like my mum lying there, just a vacant body. The cause of death listed on the death certificate was pancreatic cancer. Mum had always thought she would die of liver cancer but there was no mention of hepatitis C at all.

58. We had no problem with the funeral directors, but maybe this was due to hepatitis C being left off the death certificate. I have read that some people have faced difficulties with funeral arrangements following a diagnosis of hepatitis C.

59. Mum always told health care professionals about her infection, but always felt like she had to explain how she contracted it.

60. In the beginning, I just tried to get over the shock of what had happened by carrying on life as normal, but it was constantly on my mind. I have had to come to terms with mum's death and have found

this very difficult, for example I have only just put her house up for sale. The house is as she left it. I can still smell mums perfume.

61. Our family has always been very open and have never kept anything from one another. We therefore told my children, and they played a huge role in the care of their Nan in her later life by taking her to appointments and spending time with her.

62. My eldest son moved out just before Mum was diagnosed. I remember calling him to tell him what had happened and him just crying down the phone. I have always regretted telling him this way and wish I had waited to see him in person.

63. I found it difficult to balance my time between looking after Mum, raising my family and working. Whenever my husband and I would go on holiday, I would make a rota for the kids to look after their Nan, which they would always stick to.

64. Mum was a very proud lady, but she was ashamed of what she had. She was selective as to who she told as most people assumed she had AIDS.

65. I recall I told one of my friends who then told her mum. She then told someone else who then told everyone Mum had AIDS. It was like Chinese whispers. When we next went to Bingo together, people were staring at us. They knew something was wrong, but they didn't know for sure what it was.

66. Mum said she couldn't stand to go any more and we didn't for a while. However, I was concerned as it had become her only social outing and eventually persuaded her to go back. She carried on going until she was finally admitted to the BRI.

67. I think mum took early retirement, money was tight at the time, dad had also taken early retirement and they had to be careful with their money.

68. My work were wonderful, particularly when Mum's health took a turn for the worse. They allowed me to go to the hospital every day. My doctor signed me off work, as they knew I was caring full time for Mum. This meant that I continued to be paid over the four months I was off work. I did miss out on any overtime I would have done, but that was the only financial loss I suffered. It didn't really matter, as I got to spend more time with Mum.

Section 6. Treatment/Care/Support

69. Mums hepatitis treatment was very good, we didn't have to fight for the it and latterly when she became really ill the treatment she received was brilliant.

70. Counselling and psychological support was never made available to my mother whilst she was alive and nor has it ever been made available to me. I did receive some support from Dorothy House Hospice, but this was in relation to her pancreatic cancer.

Section 7. Financial Assistance

71. We found out that financial assistance was available from my mother's liver consultant, Dr Fiona Gordon. We applied to the Skipton Fund, and mum received the Stage 1 payment of £25,000, Sometime later, when she was diagnosed with cirrhosis of the liver, she received the Stage 2 payment, which I think was either £20,000 or £25,000. I cannot be exact with the dates. I helped Mum fill in the application; I am not sure she would have been able to do it by herself.

72. She also received monthly payments of £1,100 until her death. It meant she could pay for whatever she wanted, though she always lived very

frugally. She did use it to pay for improvements to her house, like a new carpet and windows. Her home was her sanctuary, particularly given that she didn't leave it much in her last few years. She additionally had a stair lift and handles installed with the money she received from the Skipton Fund. She felt the cold and loved having her heating on, even on a warm day.

73. I have not personally received any financial assistance from any Trust or Fund as I am unaware of any assistance for family members. My mother alone received money from the Skipton Fund.

Section 8. Other Issues

74. I believe that my mum would hope that the Inquiry holds people accountable for their actions. She would want someone to say 'it was these people', or 'this happened and it shouldn't have done'. We had heard blood was coming from American drug addicts and prisoners and have been waiting too long for the answers we deserve.

75. We have never been involved in any litigation relating to this issue.

76. During the last few months of her life, Mum's words to me were, GRO-B I know I won't be here to see the outcome of this Inquiry, but I want you to tell my story with the others". This should never have happened and took its toll on all our lives and I feel that this is why I need to tell her story.

Statement of Truth

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

Signed GRO-B

Dated 01 August 2019