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Witness Name: GRO-B

Statement No.: WITN0253001

Exhibits: WITN0253002-003

Dated:

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 22 January 2019.

I, GRO-B will say as follows:

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1940 and my address is known to the Inquiry. I live in my own home with my son. My husband has passed away. I have not worked since approximately 1980. I also have a daughter whom I adopted in 1975 when she was 5 weeks old.
2. I intend to speak about my infection with the Hepatitis C virus (HCV), which I believe I contracted from a blood transfusion that I received in 1980.
3. In particular, I intend to discuss the nature of my illness, how it affected me, the treatment that I received and the impact it has had on my life and family.

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4. The events that I detail in this statement happened a long time ago and my memory regarding precise dates has faded. The dates referred to in this statement are therefore a rough approximation on some occasions.
5. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. The Inquiry team has explained the anonymity process to me. I have given it consideration [REDACTED] NOT RELEVANT [REDACTED] NOT RELEVANT [REDACTED]

Section 2. How Infected

6. I have had three blood transfusions on three separate occasions.
7. The first blood transfusion that I received was shortly after the birth of my son on [REDACTED] 1980 at [REDACTED] Hospital in [REDACTED]. I received the blood transfusion either on the same day of his birth or the following day.
8. I had been admitted to [REDACTED] about two weeks prior to my son's birth as there were concerns about my ability to reach the hospital if I were to go into labour at home. I lived approximately 20 miles from the hospital.
9. There were also some concerns regarding my age and the fact that I had asthma. I was about 39 years old and considered to be an 'older' mum at that time. For these reasons I had a Caesarean section for my son's birth. At the time, I was also informed that I had a rare type of blood, 'A Rhesus negative'. I was issued with a green card that detailed my blood type to carry with me in case of an emergency.
10. When my son was born, I recall the doctor trying to show him to me. I do not remember much as I was in and out of consciousness for approximately three days after his birth. However, during that time, I recall

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the doctor saying, "*The bed needs tipping back and she needs more units*". I believe his reference to 'units' was in reference to blood. I also remember seeing the blood connected to me. I think I asked the doctor whether I was dying, but I cannot remember if he responded.

11. I remained at GRO-B for approximately three weeks after my son's birth. After I was discharged from hospital, my husband and I did not really talk about it and the blood transfusion that I had received. We were just glad that I was all right and that we were going home. My husband and I had been married for 19 years by that time. We had been trying to have children of our own for a long time so we were over the moon that we were able to have our son.
12. When I got home, I went to see my General Practitioner (GP) and was informed that I had post-natal depression. I was given anti-depressants and over time my mental health improved. However, following my son's birth, I was never quite well.
13. Before my son's birth, I was very active and did a lot of decorating. Following his birth, for the following 7 – 8 years I was unbelievably tired and experienced extreme fatigue. I would sleep anywhere all the time and struggled to look after my children. The fatigue that I experienced was in contrast to my previously active lifestyle. Everything just seemed to be too much. When I went to see the doctor, I was told that I was very anaemic.
14. My whole body ached a lot as well. Although I could not pinpoint exactly what was wrong, I felt generally unwell.
15. In addition, I experienced a lot of bleeding as I had my period nearly all of the time after my son was born. This was accompanied by pain in my pelvic area. Within a month, I would typically only have up to three days where I would not experience bleeding.

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16. At times, the bleeding would be very heavy and I would stay in the bathroom for an hour. I could only wear black trousers. It caused me huge difficulties. At times I felt like I would not make it home in time when I was out. My husband had to help me with the grocery shopping, as I could not do it on my own.
17. As I experienced these symptoms I continued to inform my GP but I was always told that everything was fine. In early 1987, I saw a Locum GP about my symptoms and he had a different attitude to my health problems. He said that my blood levels were very low and made an appointment for me to see a doctor at Wexham Park Hospital on the same day for a hysterectomy.
18. When I went to Wexham Park Hospital, the doctor told me that they could not do the hysterectomy as my blood levels were too low. Instead, I was given a blood transfusion. I was told that my blood levels needed to be 'boosted' before they could operate.
19. I returned home after the blood transfusion and in a very short space of time, I think about a week later, I returned to Wexham Park Hospital for the hysterectomy. Again, my blood levels were checked and I was told that I needed another 'Top up' as my blood levels were still low. I received another blood transfusion and then underwent surgery for a hysterectomy.
20. After the hysterectomy procedure, I was advised that I had a bad pelvic infection that had gone into my bowel. I was told that during the operation, they did antibiotic washes through my bowel to treat the infection.
21. Following the hysterectomy in 1987, I was still very unwell. About 18 months later, in 1990, my GP said that I should be feeling better by then but I was not. He did a test on my thyroid function and found that I had an under active thyroid. He gave me tablets for it, which I still take to this day.

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22. A few years later, I experienced chest pain and saw my GP regarding the matter. He referred me to a heart specialist at Wexham Park Hospital. The specialist examined me and said that there was nothing wrong with my heart. Instead, he said that I had Sjogren's syndrome, an autoimmune disease.¹ I received this diagnosis in or around 2000, I cannot recall an exact date.
23. There are many symptoms associated with Sjogren's syndrome, including chest pain, fatigue, dry eyes and a dry throat. I was given eye drops and continued to experience fatigue. I would sleep up to 10 hours at a time and would still feel tired afterwards.
24. Following my diagnosis of Sjogren's syndrome, I went to Wexham Park hospital ever year and sometimes more frequently for check up appointments. Sometime in or around late January 2006, during one of my regularly check up appointments, my doctor at Wexham Park Hospital reviewed my blood tests results and said that my liver count was very high. He asked me if he could do a test on me to see if I had HCV to which I agreed.
25. He carried out a test that same day. As soon as I returned home that day, my doctor called me back and informed me that I was HCV positive. He told me that he needed to see me. He said that he would wait for me at Wexham Park Hospital and asked me to come back to see him that same day.
26. I went back to my doctor at Wexham Park Hospital accordingly. He explained that I could go on a treatment programme to clear the HCV. He said that I did not have to have it and that it was up to me. He said that the

¹ Sjogren's syndrome: "An autoimmune disease that classically combines dry eyes, dry mouth, and another disease of the connective tissues... Inflammation of the glands that produce tears (the lacrimal glands) leads to decreased tears and dry eyes. Inflammation of the glands that produce saliva in the mouth leads to dry mouth. Sjogren's syndrome can consequently be complicated by infections of the eyes, breathing passages, and mouth." Medical Definition of Sjogren syndrome (2017, January 24). Retrieved from <https://www.medicinenet.com/script/main/art.asp?articlekey=8006>.

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treatment was harsh and that he was concerned about whether I would be able to cope with it given my age. I was in my 60's at the time. However, the doctor also said that if I did not have treatment, my condition could get worse. I was told that I could receive the treatment from either Royal Berkshire or Stoke Mandeville.

27. I also underwent a biopsy test on the same day. I cannot recall whether I had to go back to the hospital for the results of the biopsy test. I think I may have been called and informed that the biopsy confirmed that I was HCV positive but that I did not have cirrhosis.
28. Overall, I have no concerns regarding the way in which my doctor from Wexham Park Hospital told me that I had HCV. I was happy with the way in which he communicated with me about my diagnosis. Although, at the time I felt like I was in a dream. I could not believe I actually had HCV.
29. I decided to have treatment and picked Royal Berkshire as the place to receive treatment from. My doctor at Wexham Park Hospital accordingly referred me to the Royal Berkshire Reading Hospital for a treatment programme.
30. After my diagnosis, I did not have to wait long to be put on the treatment programme. My treatment at Reading Hospital started on 8 March 2006. Shortly before that date, I saw a specialist at Reading Hospital, Dr [GRO-D]. Again, Dr [GRO-D] said that he was concerned about putting me on the treatment programme given my age and strength. He did say that there was a good chance that the treatment would clear the HCV. I still wanted the treatment so he made an appointment for me with the specialist nurse at the hospital to commence the treatment. I think my first appointment with the nurse, [GRO-D], was on a different day.
31. I think I may have also been asked if I had received any blood transfusions in the 1980s to which I said yes. I received a letter around that time which confirmed that I had received two blood transfusions. The letter enclosed

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two records confirming the details of those blood transfusions. I exhibit the letter and its enclosures as **WITN0253002**. The letter noted that according to my records, I received a blood transfusion on [GRO-B] 1980 and a further blood transfusion on 14 April 1989.

32. Apart from being told that the treatment for HCV was tough, I do not recall being told about the exact side effects of the treatment either from my doctor at Wexham Park Hospital or by Dr [GRO-D] or [GRO-D] at Reading Hospital.
33. When I was diagnosed with HCV, I read a lot and was self-active to find out more about it. None of my doctors gave me information to help me understand it, or provided me with information on how to manage the infection. I am of the view that more information should have been provided to me and looking back on it, they should have done more.
34. In terms of information regarding the risks of others being infected by me, the specialist nurse, [GRO-D], at Reading Hospital provided me with some information when I first saw her. She said, that I had to be very careful if I bled anywhere. She told me to wash the bathroom basin with bleach if I bled while brushing my teeth and to bleach everything if I bled. She advised me not to share razors or towels as well.
35. I was also told that any children that I may have had after I got HCV or my partner could have HCV. They offered to provide testing services for my husband, but he refused and was never tested for HCV.
36. My treatment programme for HCV commenced on 8 March 2006 and finished on 19 December 2007. I exhibit a card that details the dates of appointments that I attended for treatment as exhibit **WITN0253003**.
37. My treatment consisted of Interferon injections and Ribavirin tablets. During my appointment with [GRO-D] at Reading Hospital on 17 May 2006, she injected me with Interferon to show me how to do it. During the

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following few appointments I had with her, I injected myself with Interferon while she watched to help me. After June 2006, I injected myself with Interferon at home and only attended appointments at Reading Hospital once a month.

38. I cannot recall whether I required the injections every day or every week. I took the Ribavirin tablets every day although I cannot recall how many tablets I had to take each day.
39. GRO-D provided me with some assistance regarding the weight loss I was experiencing as a result of the treatment. I have detailed the side effects of the treatment that I experienced further below. However, other than that, I was not provided with any information on how to manage or deal with the other side effects I was experiencing.
40. At the time, I did not think much about the way in which I was treated. I felt so ill that each time that I went to the hospital, I just wanted to get back home and lie down. In hindsight, I am of the view that I should have been given more information to help me manage the side effects I experienced.
41. I had a blood test either on my last date of treatment, 19 December 2007, or shortly afterwards. I went back to Reading Hospital sometime between January and February 2008 for the results of the blood test and the outcome of the treatment I had received. I was told that the HCV had been cleared. However, I was advised that HCV has a habit of 'hiding' in the tissues and that it could reappear within 3 months.
42. I therefore had to return for another blood test sometime between April and May 2008. I did not have to return to Reading Hospital for the results of this final blood test. I think that a nurse telephoned me to confirm that I had the all clear.

Section 3. Other Infections

43. I was diagnosed with HCV after my diagnosis of Sjogren's syndrome. I do wonder whether I had HCV prior to my diagnosis of Sjogren's syndrome and whether it simply lay dormant during that time. I believe this as prior to 1980, my health was good and it was only after 1980 that my life changed a lot. When I started to become really ill, I remember that my husband made the comment that perhaps I had AIDS from the blood transfusion I received in 1980. Even before my diagnosis of HCV, he also commented that the sides of my face looked very yellow. I did not think much of it at the time.

44. While I will never know for sure, I also question whether the Sjogren's syndrome was a knock on effect from the blood transfusion I received in 1980. Although I have been cleared of HCV, I am still living with Sjogren's syndrome and it will never go away. As it affects my immune system it causes a lot of problems. I was very ill about two years ago when I got the flu, which then developed into a chest infection. I was admitted to hospital and it took me a long time to recover. The doctor at that time told me that my Sjogren's syndrome was complicating everything they were trying to do to make me better.

45. I also suffer from a lot of pain as a result of Sjogren's syndrome. For example, if I knock my leg on something, it can hurt for up to an hour. I also still sleep a lot as a result of my condition, sometimes up to 10 hours at a time.

46. As well as suffering from Sjogren's syndrome, in 1995, I was very ill as I had gallstones. I think I first went to GRO-B for scans that revealed that I had gallstones. I cannot recall exactly when in 1995 this occurred. I was told that I needed to have them removed and was referred to Hillingdon Hospital for surgery. I was put on the Hillingdon Hospital waiting list for surgery and had to wait for a long time.

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47. During the time I waited, my mother had a stroke and was in hospital for two weeks. Within three months of having the stroke, she passed away. While she was unwell following the stroke, I decided not to have surgery during that time, as I wanted to be with my mother and support her. When she was in hospital, I remember that I only ate dry crackers to avoid feeling ill as I experienced pain whenever I ate.
48. About three months after my mother passed away, I eventually had surgery at Hillingdon Hospital for the removal of my gallstones. Again I cannot recall an exact date but the surgery would have been sometime in 1996. I was told that I had about 100 'pea-sized' gallstones and as I had so many, they could not do a keyhole surgery. Instead, they had to make a surgical cut to remove them. I was ill for approximately a year in total before I had the surgery. As a result, I had lost about 2 stone in weight during that time. After the surgery, the pain went away and I was able to eat again.
49. I mention the fact that I suffered from gallstones as I am aware that the gallbladder is very close to the liver. Again, I am unsure if it was another medical complication that related in some way to the HCV I was later diagnosed with.
50. Personally, I believe my health has been generally affected after the blood transfusion I received in 1980 and also as a result of the HCV I have contracted. I have never been right since that blood transfusion.
51. I look at other people my age who are in better health and think that I should be too given that I am not a drinker or smoker and ate properly throughout my life. To some degree, I think that the HCV in particular is responsible for my overall general ill health. My husband always thought that as well.

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Section 4. Consent

52. I have been asked whether I believe I have been treated or tested without my knowledge or consent. When I signed documents for the Caesarean section I had in 1980 for the birth of my son, I do not recall signing anything to say that I would have a blood transfusion if required. However, I do acknowledge that this may have been contained in the 'small print' of the document I signed. I am also unsure if my husband signed anything for me while I was in and out of consciousness during the days following my son's birth. He could have signed something to provide consent for the blood transfusion I received but I do not know for sure.

53. In the circumstances, I understand that if they had not given me a blood transfusion following the Caesarean section, I could have died. After the procedure, I was just glad to get out of there.

54. With regards to the treatment I received for HCV, I do think that I was treated without sufficient information. I think more could have been done to inform me. They could have provided me with leaflets to read and advised me on things that I could or could not do. I appreciate that some people may not want to know all of the details associated with the treatment, but I did want to know and would have rather known everything about it before receiving the treatment.

55. While I would have signed documents to consent to the various treatments I have received over time, I do admit that I did not always read the small print of those documents. I always felt rushed and felt like everyone else was in a hurry.

56. I have also been asked whether I believe I have been treated or tested for the purposes of research. As far as I am aware, there is no indication that I have been treated or tested for research purposes.

Section 5. Impact

57. When I first went to Reading Hospital for treatment for HCV, I was told that I was 'lucky' as Royal Berkshire were paying for my treatment. I certainly did not feel very lucky at the time.

58. I experienced bad side effects from the HCV treatment that I received. It was a gradual process. During the first month of treatment I was fine. I then started to sleep a lot and lost my appetite. I felt generally ill and also experienced partial hair loss.

59. I did not like seeing anyone during that time and for some time after the treatment until I recovered from the side effects. I did not look good as a result of the weight loss and partial hair loss. I felt like a prisoner in my own home.

60. As I progressed through the treatment, the degree of illness worsened as the side effects became more extreme. I felt lethargic, generally weak and may have also had headaches. The thought of eating was horrendous at the time and I was worried that I would become anorexic. My mind went into overdrive.

61. The specialist nurse wrote to my GP for a prescription to help me with the weight loss. She arranged milk shakes for me that contained vitamins to help me put on weight. I was supposed to have four a day but could only managed one a day at best.

62. On 9 May 2007, I saw Dr GRO-D at Reading Hospital as I was really ill by that stage. I had lost 3 stone in weight. I was asked whether I wanted to stop the treatment but I said no. My husband wanted me to stop but I carried on anyway. I thought that as I had come that far, I needed to continue. I thought I was going to die if I stopped the treatment. At times I

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thought I was going to die anyway. I remember at one point, I threw away belongings like my food mixer as I thought I would never use them again.

63. After approximately 18 months of treatment it took some time to recover from the side effects. I forced myself to get out of the house as I would otherwise sleep all day.

64. I only told my daughter, son, husband, my brother and his wife about the fact that I had HCV. I have not told anyone else about it because of the stigma associated with HCV. My husband's family still do not know that I had HCV.

65. I worry that people will judge me if they knew and that they would assume I was an excessive drinker or drug user. People can be quick to form an opinion of you and they can be unbelievable in what they can say to you. For these reasons I did not want to tell anybody about it. I worry that I will forget and mention the fact that I had HCV in passing while talking to someone. I worry that I will break the 'secrecy' of it.

66. When I went to Reading Hospital for blood tests during my treatment for HCV, I received a card each time while I waited which had a big red sticker on it to say that I was HCV positive. While it is fair that people taking my blood needed to know that I had HCV, I held the card close to me so other people would not see it. I used to sit in the corner of the waiting room to try and avoid people seeing the card and finding out that I had HCV.

67. I feel like I will never be free of it and it is constantly being brought up and on my mind. Every dental form and hospital form that I have completed, the first question is always whether you have had HCV. I declare it every time although it has not caused me any problems at dental appointments. I have never been made to feel bad by the dentist after declaring the fact that I had HCV.

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68. I receive letters from my doctor and even to this day, the letters always make note that I had HCV in the subject line of the letter. It is never left off the letter and I do not understand why it is always referred to even though I have now been cleared of it. I have had many other illnesses but those things are not continuously referred to in my doctor's letters.
69. It makes me feel 'unclean'. It also makes me believe that it could resurface. I think why else is it always mentioned in my doctor's letters to me. Even now, every time I have a check up for Sjogren's syndrome, I always ask the doctor how my liver is. This sometimes provides me with some reassurance that the HCV has not reappeared. However, whenever I get ill, I still worry that it may be connected to HCV and worry that it is reappearing. I feel like I am constantly living with that fear.
70. Since my treatment for HCV finished, I can honestly say that there has not been a single day that I have felt well all day. I suffer from a bad back and sore legs at present. While it is hard to say how much is attributable to the HCV or blood transfusion, I am of the view that my overall general health has been affected by HCV.
71. I do think that the HCV had an impact on my family as well. When I had the treatment for HCV, my husband took me to Reading Hospital for my appointments. At the time he had a medical condition and needed to take water tablets daily. Some days when he took me to Reading Hospital, he could not take those tablets. After my diagnosis of HCV, my husband was also paranoid and worried about whether I would get another infection or get sick. While he worried about me, he never took a test himself to see if he had HCV.
72. It was not long after my treatment for HCV ended when my husband passed away from a different cause. He passed away next to me in 2009. It was a very tough time for me and my daughter had to stop working to look after me. I was in a really bad mental state at that time. We were

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dealing with people regarding our pension at the time and I found them to be extremely harsh and difficult to deal with.

73. I believe that if I had not had HCV and so many health problems following the blood transfusion I received in 1980, I may have worked following my son's birth and I may have had more of a social life. I felt like those things would have helped me during the time my husband passed away and helped me in dealing with the pension issues I experienced at the time.

74. I do still rely on my children for support. I talk to my son about my health more now as he lives with me. While he keeps to himself about it all, he has been my technological source and will do online research for me whenever I have questions. I also ask my daughter questions as she works at a doctor's clinic.

75. In terms of financial affects, my family and I did struggle. My husband had worked as a representative for several different companies over time including a rug company, car company and food company. We own the home that I currently live in and were able to pay the mortgage off before he was made redundant from his last post. If that had not been the case, after my diagnosis of HCV I think we would have had to move due to our financial difficulties.

76. As Sjogren's syndrome affects the amount of saliva that is produced, I was required to have dental appointments every three months. It was very expensive and I was initially advised that I could claim back the cost of the appointments by applying to the National Health Service (NHS). I tried to apply but I was unfortunately told that the cost could not be claimed back.

77. We had to live within our means. I have not been on a holiday for at least 12 years.

78. I recall going to a barbeque one day at my brother's house. A person that did not know that I have had blood transfusions or that I had HCV made a

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comment that she would never have a blood transfusion and accept someone else's blood. I asked her what about if she was dying. She said that she still would not accept a blood transfusion. Inside, I was very annoyed. I wanted to say that she had never been in that position before so did not know what it was actually like.

79. I had a religious background growing up. To get through what I have been through I have simply believed that things are going to be all right.

Section 6. Treatment/Care/Support

80. I do not feel that there were any obstacles in place for me to obtain treatment for HCV. After my diagnosis, it was a very fast process. I was able to start treatment very soon after I was first told that I had HCV.

81. However, a difficulty that I faced was reaching Reading Hospital for the treatment. While my husband and I did have a car, we were never offered any help to cover the fuel cost. We were financially struggling at the time and the journey to the hospital from our home was very long. If we had not had a car, I am not sure how we would have managed at all as no transport assistance was offered.

82. I have never been offered any psychological support either. I do not even know what that would entail. I would be interested in exploring the possibility of using such support if I do not need to travel for it.

83. The Inquiry team have informed me about the work of the British Red Cross (BRC) and that they are attending the Inquiry's hearings. I have been informed that I can call the BRC to seek some support and I have been provided with their contact details. I am interested in making contact with them to explore whether it is something that could be beneficial for me and I intend to make contact with them.

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Section 7. Financial Assistance

84. I received financial assistance from the Skipton Fund. I believe that the Skipton Fund made contact with me first by writing to me, and then speaking to me by telephone. They introduced themselves to me and said that I may be entitled to an ex gratia payment.

85. I was sent paperwork to complete for the payment. I recall having to get my doctor to complete some sections of the paperwork and I had to ask him for details such as when I was diagnosed with HCV. I did not encounter any difficulties in completing this paperwork for the Skipton Fund.

86. I then received a stage 1 ex gratia payment of £20,000 in July 2006. I remember that I was told that if I got cirrhosis, I could get more money.

87. I have been asked whether there were any pre-conditions attached to the payment I received in July 2006. I was not aware of any pre-conditions attached to that money at the time. I have also been asked whether I am aware of the meaning of an 'ex gratia payment'. I did not know the meaning of the term when I received the stage 1 payment from the Skipton Fund. The Inquiry team have now explained to me its meaning. I am now aware that it means that the payment comes without accepting any blame or responsibility.

88. When I received the money from the Skipton Fund in July 2006, it did help me as my family and I financially struggled. In hindsight, it was not enough when I consider how much time had passed before I was even told that I had HCV.

89. On 14 November 2016 I received an additional payment of £3,000 plus £500 as 'winter fuel' payment, which is now on-going.

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90. In 2017, I received quarterly payments of £675. I am aware that on 20 October 2017, the Skipton Fund moved to the England Infected Blood Support Scheme (EIBSS).

91. I also required some dental work apart from the three monthly check up appointments that were required due to my Sjogren's syndrome. I believe that the Skipton Fund paid for my dental work but I cannot recall when this occurred.

92. Overall, with the HCV, I am always aware of it. It is almost a kind of abuse on your body. Although every body makes mistakes, it seems like this one is on another level and sometimes I've wondered about the fact that I've kept the secret as only my children, brother and sister in law know. The authorities have never done enough in my mind. What would be enough? Although, I do acknowledge that the money I have received has helped me and has made my life easier.

Section 8. Other Issues

93. In terms of what the Inquiry is doing, I do not know how it could ever be put right. Too many people have died. I do not know if what ever is done will be enough. No one can bring back those that have died.

94. In summary, the documents that I have referred to in my statement are as follows:

- a) **WIN0253002**: Letter and enclosures from Dr S Levi, dated 26 April 2006, confirming blood transfusions that I have received; and
- b) **WIN0253003**: HCV Treatment Programme Card from Royal Berkshire detailing appointments I attended for HCV treatment.

Statement of Truth

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

Signed GRO-B

Dated 21/3/2019.