Witness Name: GRO-B

Statement No.: WITN0369001

Exhibits: nil

Dated: 01/03/2019

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 23 November 2018.

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

Section 1. Introduction

1. My name is GRO-B I am 62 years of age and live with my wife. My date of birth and address are known to the Inquiry. I am retired and occupied with voluntary activities, mainly connected with our church, as energy levels permit. My wife is a hospital doctor (associate specialist oncologist), at present working two days per week. We have four children aged between 25 and 34 years who no longer live at home. I was born and brought up in GRO-B West Yorkshire before moving away in 1975 to take my first degree in GRO-B I have an MA in mathematics from GRO-B University and an MSc in statistics from Edinburgh University. I moved to Edinburgh in the summer of 1978 to do the MSc. Between 1979 and 1983 I worked at GRO-B first as a temporary lecturer in statistics and then as a research associate. In 1983 I joined the civil service at the GRO-B as a senior assistant statistician and then moved on promotion to statistician to what was then the GRO-B in October 1986. I worked for the successor departments thereafter. After my medical

retirement in 2008, I was treated a third time with interferon and ribavirin. This time the virus successfully cleared. I was able to recuperate and have since undertaken voluntary work, including setting up and managing a Foodbank for five years (2011 until 2015).

2. I intend to speak about my infection with the Hepatitis C virus (HCV), which I contracted through contaminated blood products. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life.

3. I confirm that I have chosen not to be legally represented.

Section 2. How Infected

4. I suffer from severe Haemophilia B, as I have less than 1% clotting factor IX. Over the years it has been rated at different times as mild, moderate, moderately severe and severe, probably due to errors in testing for small amounts of factor IX. Probably <1% is reasonably accurate.

5. I was diagnosed at 3 years of age in 1959. I was first given factor IX concentrate probably in 1975, which is the year I was referred to the haemophilia centre in St James's, Leeds. The first available medical record of my receiving a dose of factor IX is July 1976.

6. I have received very many doses of many different factor IX products from several different hospitals over the years since then.

7. I was first given the HCV diagnosis in November 1990. It seems almost certain that I was infected with Hepatitis C through treatment with infected factor IX. I am not aware of anything else that might have caused it. My understanding is that a specific HCV test only became available around 1990.

8. In 2018, I requested all of my medical records. I noted that a stored blood sample I gave in July 1986 was subsequently tested in 1991 and found positive for HCV.

9. My records show that I had consistently raised liver function tests (SGPT/ALT) over many years. The earliest reference to this I can find in my medical notes is July 1978, but I cannot recall that I was ever told about raised liver function tests until November 1990. Infection with HCV is therefore highly likely to have taken place between 1975 and 1986.

10. In 1984 I was found to be hepatitis B positive. As with the HCV, this is highly likely to have been through infected factor IX concentrate. The hepatitis B spontaneously cleared within a few months. I will expand on all of this below.

11. When I was young and had a bleed the only thing that could be done was to rest the joint and let it settle on its own. I would then start very gradual exercises to get it back to normal. It could take a month or longer, particularly if it was a walking joint like my ankle. I would have to rest the affected joint as much as possible and occasionally this led to time off school for ankle or psoas bleeds.

12. In my school years I sometimes saw rheumatologists when I had a joint bleed, because bleeds cause swelling, stiffness and pain in the joint. Of course I did not know then what I know now about haemophilia and unfortunately the doctors I saw had limited knowledge too.

13. When bleeding episodes had settled and the joint was recovering I would sometimes be given wax baths (for my fingers) or microwave heat (elbows, ankles) to help clear the swelling.

14. One rheumatologist, Doctor Humberstone, (at either the Halifax General Hospital or Halifax Royal Infirmary, I cannot now remember which) knew there was a Haemophilia Centre at St James's Hospital, Leeds. He referred me to Dr LM Swinburne, who was the director there in May 1975, after a particularly bad ankle bleed. That was while I was working as a clerk in GRO-B following my GRO-B entrance exam and before I went up to GRO-B in autumn 1975.

15. It was the first time I ever saw a haemophilia specialist. Dr Swinburne diagnosed a joint bleed but said it had settled and so Factor IX was not required.

16. I think that my first treatment with Factor IX would perhaps have been later in 1975. (I cannot give details of treatments in Leeds around that time because Leeds Teaching Hospitals NHS Trust cannot find any records about me, except for three pages relating to 1979.)

17. From then on I knew that Factor IX was available if required by visiting St James's, Leeds.

18. Later an arrangement was made for a supply of Factor IX to be kept on a ward at the Halifax General Hospital. I could then phone and visit the ward when I needed to have someone reconstitute and inject the Factor IX. I assume the Halifax supply was obtained via St James's Hospital in Leeds and under their supervision.

19. According to the medical records I received from Calderdale and Huddersfield NHS Foundation Trust, the earliest recorded dose of Factor IX I received in Halifax was in October 1976. There were probably only a very few such occasions in Halifax. I cannot remember how often I received Factor IX at St James's but as stated above, Leeds hospital records have not been found.

20. Between 1975 and 1978, while I was at GRO-B University, I was treated under Dr Chalmers at Addenbrooke's Hospital. There were eighteen episodes of treatment during that period, according to records from Addenbrooke's NHS Trust. I think there may also have been one occasion during this period when I visited a Haemophilia Centre in Manchester. This was after an ankle bleed while on holiday in the Lake District, but Manchester Universities NHS Foundation Trust have not been able to trace any records for me.

21. In the summer of 1978 I went to live in Edinburgh and nearly all of my Factor IX between 1978 and 1986 came from Edinburgh Royal Infirmary.

22. I had one particularly nasty bleed into the left knee at Christmas 1979, so I used a lot of Factor IX over the following six months. Factor IX treatment for that episode began in Halifax, then moved to Leeds, then to Edinburgh. It came as a result of an injury, which in a normal person would probably have been quite minor. At first I hoped the injury had not started a bleed, but over the following hours it was clear that one had. I went to the Halifax General Hospital and received one dose of Factor IX. It was a small dose (600iu) and it had little effect. The pain became unbearable and I had to be admitted to St James's a day or two later, where the joint was aspirated and I had further Factor IX and bed rest.

23. After a week or so I was transferred to Edinburgh Royal Infirmary. I spent around a further five weeks in total as a hospital in-patient over the next six months while my knee was sorted out. In between, I had a full-length pot on my left leg and was carrying out my job. At the time I was a GRO-B

24. In spring 1979 I was shown how to reconstitute factor IX and to inject myself, and I have done so frequently ever since then. Prior to this I didn't handle the Factor IX as it was injected for me.

25. From October 1986 onwards, I transferred employment from the GRO-B to the GRO-B Since this time all the Factor IX came exclusively from the Royal Hallamshire Hospital in Sheffield, or was arranged by them (one exception was a dose given in Exeter in about 2010, but that was long after the blood products had ceased to be infective).

26. Even when I was abroad in Luxembourg during 1991/92, I made contact with a doctor out there in case of emergency, but brought supplies of Factor IX over from Sheffield.

27. For many years I treated bleeds about twice a month on average, followed by a repeat dose when necessary. From time to time over the last few years, and continuously for the last few years, I have

been having twice weekly and now once weekly prophylaxis. I have had far fewer bleeds while on prophylaxis.

28. In May 1984 I was invited by the Haemophilia Centre at the Royal Infirmary of Edinburgh to have a vaccination against Hepatitis B. I understood that this was also being offered to other haemophilia patients. I had a blood test at that appointment and it was found that I already had acute Hepatitis B infection. This was the first time I had tested positive for Hepatitis B. Looking now at my Lothian medical notes I see for example that in August 1983 I had been clear of it. It seems highly likely that this was contracted from an infected dose of Factor IX and no other potential cause was apparent.

29. I was not aware of any symptoms whilst I had the infection and the Hepatitis B cleared spontaneously. My medical notes show further positive Hepatitis B tests during June and early July, but then from mid-July onwards the test results show past infection with Hepatitis B, but no current infection. My wife was also given a Hepatitis B vaccination in 1984, as she was pregnant.

30. Until 1985, all the blood products I received were from pooled human blood donations and not specifically treated to deactivate any viruses present.

31. I think they were just going on to heat-treated Factor IX in my last year or two in Edinburgh (1984/1985). I remember Doctor Ludlum asking me if I would, on a voluntary basis, take a large dose of the old untreated Factor IX and then a dose of the new heat-treated Factor IX. This was so that they could check that the heat-treated product was as effective as the untreated product. They felt the heat treatment might degrade the product slightly so it might not be quite as effective. I consented to this and as far as I know the findings were as expected, that heat treatment led to a small loss of activity. (I was not being treated prophylactically at this time).

32. I think Dr Ludlum informed me of possible risks, but this was obvious in any case. As far as I know there is no other reason to heat-treat Factor IX apart from deactivating viruses that might pose a risk. He also pointed out that I would only be taking another dose of the same Factor IX I had already received large amounts of over the previous years. I was perfectly happy with this, but could have refused had I wished. Hospital records contain a consent form dated July 1985 for a dose of heat-treated factor IX, which was probably this one.

33. After transferring to heat-treated factor IX I believe I then stayed on it until the recombinant products came in. I am not sure exactly when that was.

34. I think I was told on more than one occasion in the 1970s and 1980s that I had tested negative to what was known as "non A, non B

Hepatitis", I recall Doctor Davies telling me this. He was in Edinburgh Royal Infirmary when I arrived in Edinburgh in 1978. I do not know the nature of that test. Dr Davies was on the point of retiring by then and he was to be replaced by Doctor Ludlum. That would probably be in 1978 or 1979.

35. Dr Ludlam was certainly there by the time I was in hospital, with my knee in the first half of 1980. I also recall seeing a Professor Girdwood when I was in Edinburgh. I cannot recall any specific occasion after that when I was told the results of a hepatitis test, until the appointment in Sheffield in November 1990 described below. I made it clear that I wanted to know of any abnormal test results, if and when they were found.

36. I do recall having a conversation with Doctor Ludlum that my wife also attended, which was at the time AIDs was first being discussed. He said that not much was known about AIDs yet, but that it seemed it could be transmitted through the blood products. He thought that sex transmission was not very likely, but he thought we ought to use a condom. I cannot put a date on this conversation but I think it would have been in the mid 80s. I do not recall if any warnings were given to me prior to this about the risk of infection and secondary infection.

37. As an aside, I should say that I trusted Dr Ludlam at the time and have had no reason since to change my mind, although I have not met him since 1986. He was both clever and caring. Between 1980 and 1983 he was slightly involved in a heart disease research team led by Professor Oliver. GRO-B so we had an occasional professional contact as well as doctor-patient.

38. I was distressed to see just prior to the Penrose Inquiry, that he was being accused of some sort of malpractice by a patient. I know none of the details, but from my own knowledge of Dr Ludlam at the time I would not be inclined to believe allegations against his integrity.

39. Neither my wife nor I ever recall being told that I had abnormal liver function tests before the appointment of November 1990. I think I had been told of the risk of jaundice, and that people could sometimes get short-term flu-like symptoms from the treatment. If liver function tests were ever mentioned I think it must have been low key. Possibly the message might have been along the lines that although many people receiving blood products seemed to have raised LFTs there did not seem to be any significant adverse effects and it was just one of those things.

40. I was therefore surprised when I got my medical notes in 2018 to see that my ALT (also known as SGPT) had been consistently raised over many years. It was mentioned in the referral letter from Dr Chalmers of Addenbrooke's to Dr Davies of Edinburgh when I moved to Edinburgh in 1978.

41. That letter, dated 5th July 1978, includes the paragraph: "He was tested earlier this year and found to have the Australia antigen and antibody negative. His liver function tests were mildly disturbed and he had a total bilirubin of 14, which is our upper level of normal, and alkaline phosphatase of 53, which is well within our normal range, and an SGPT of 120, where our upper limit of normal in males is 38. *We find that the majority of our patients who are on fairly frequent intravenous infusion of protein do run a moderately elevated SGPT* [italics added]."

42. Given that my first dose of factor IX was in 1975 or 1976, and that a stored blood sample taken in July 1986 showed positive for HCV when subsequently tested in 1992, it seems that infection must have happened over the period 1975 - July 1986. The raised liver function tests reported in July 1978 may suggest that infection occurred prior to July 1978. The HCV was later determined to be genotype 3a.

43. There is incomplete information on product names and batch numbers in my medical notes. Records of treatment given at Leeds prior to 1979, which may probably include the first dose I ever received, are entirely missing.

44. In November 1990 I attended an appointment with Professor Preston at the Sheffield Haemophilia Centre. The first I became aware of my HCV was during a routine appointment with Professor Preston, with Doctor Makris sitting in. I recall Professor Preston probed me about my alcohol intake at the time, which is close to zero because I am teetotal.

45. I expressed annoyance at the suggestion that my raised liver function test could be due to excessive drinking: I felt it was adding insult to injury since it seemed likely that if I had tested positive for HCV then the raised liver function test would have been caused by the HCV infection, contracted via infected blood products. I cannot remember what he said in response.

46. I also told them at the same appointment, that I thought I had made it clear from when I first attended the Haemophilia Centre, that I wanted to know of any adverse findings of blood tests immediately. What Professor Preston was saying was that they had known about the virus, or at least abnormal liver function tests, for some time and had not told me until that moment. His response was that he thought that I had just asked to be told about AIDS, and that until recently they had not known enough to give any reasonable explanation of what test results like mine actually meant. A fair point in some ways, but I did not feel satisfied at the time.

47. It makes more sense now, in the light of the fact that my liver function tests had been abnormal for more than ten years by then. I guess haemophilia doctors thought in the early days of treatment that

abnormal liver function tests were just something that happened, that they did not seem to mean much or have any adverse effects. Only gradually did it dawn that there was a serious underlying problem.

48. I believe I was told in November 1990 because they had then developed a test for Hepatitis C. I cannot remember specifically giving consent for a Hepatitis C test, but had I been asked I would have given consent.

49. I think there was an issue over how much patients wanted to know about things like AIDS, because they may have to pay higher insurance premiums or face stigma, if they knew they had some problem.

50. I made it clear to haemophilia doctors who treated me in Edinburgh and Sheffield, or so I thought, that I wished to be told if there ever was anything to tell. I do not know whether they particularly noted it in their records, but I assume so as it was an important point to me.

51. I was also concerned at the time that the one-year secondment abroad to GRO-B in Luxemburg that I was in the process of arranging, might be jeopardised. In fact, the secondment went ahead successfully.

52. They went on to explain that most people had no symptoms from HCV and that it might take 15 to 20 years for anything to develop, but that it might damage my liver longer term. I felt at the time that I had gone into that appointment well and left it ill.

53. Please note that I have described one appointment in detail here. The standard of care I have received from Sheffield Haemophilia Centre before and since, have been excellent. I get on very well with Professor Makris and all the other staff. The same goes for care I have received at all the other centres I have attended.

54. After being told in Sheffield in 1990 that I had HCV, my wife was offered testing for the virus. She has been tested a few times since then and is negative.

Section 3. Other Infections

55. On three occasions I have been told that I have received factor IX that was manufactured from blood potentially infected by vCJD.

56. In January 2001 Dr Makris, told me in person and by letter, that a UK blood donor had recently been found to have vCJD. However there were no reports of vCJD in haemophiliacs or other recipients of blood transfusions or blood products. He asked whether I wished to be told whether I had received any implicated batches, and I said I did.

57. Following this, in October 2004 he informed me that I had received a dose of an implicated batch: this was batch FJA4239B of product brand name 9A. This was released on 9th July 1993 and I was given 2940iu of in on 22nd March 1994.

58. Thirdly, in November 2004 Dr Rosie Dennis of the Edinburgh Haemophilia Centre wrote to Dr Makris at the Sheffield Haemophilia Centre following a review of their records. This was to say that I had received factor IX from UK sourced pooled factor concentrate. My GP was informed because I was regarded as being "at risk for vCJD" for public health purposes. I did not appear to have received any of the implicated batches of treatment in Scotland. I have not been unduly worried by any of this and no issues have arisen to date. I have told my dentist.

Section 4. Consent

59. I believe that the doctors and nurses caring for me over the years have always done so in good faith and with my best interests at heart.

60. I believe I have been given adequate information according to what was understood at the time by the medical professionals caring for me. The one apparent exception is that neither my wife nor I ever recall being told that I had raised liver function tests until I was told at my appointment at the Royal Hallamshire Hospital in November 1990. My medical records, which I obtained in 2018, show that I had run raised liver function tests since at least July 1978. I cannot account for why I would not have been told. It is possible that my wife and I had both forgotten, which seems unlikely, or perhaps that the information was presented as being of little clinical significance? I have no reason to believe that any other relevant information has ever been kept from me.

61. I have given my consent to treatment on the basis of the information given to me and that I had and have continuing trust in the people treating me. I do not believe I have ever been treated without my consent.

62. In terms of testing, I have always given consent to tests and have expected to be told of any significant test results.

63. I have on occasion consented to my blood samples being stored. This presupposes that they may have subsequently been tested and I would not have expected to have been asked for additional specific consent for such testing. I would expect to hear if any test results were of significant interest or likely to have any impact on me.

64. I have been professionally involved in research, as a statistician, all of my working life I am positive towards research. I am prepared to give

blood samples or take new treatments to aid research, as well as in my own personal interests.

65. I have always expected to be given full information about any test or treatment given, primarily for research purposes so that I could give proper consent. I have no reason to think I have ever not been given such information or ever given any test or treatment without my consent.

Section 5. Impact

66. I did not notice any ill effects from HCV until about 1997, though the side effects of treatment for it in 1994 were unpleasant. From the late 1990s when symptoms began to appear until 2008 when the HCV was finally cleared, I had a fairly horrible time. This had knock-on effects on my wife and children, particularly the younger two. I will describe the impact in more detail in the paragraphs below.

67. In March 1994 I had a 24-week course of Interferon. This was to try to mitigate or prevent any future effects of HCV. Not because I had noticed any symptoms of the virus, because I had not at that point.

68. The side effects of the treatment were moderately unpleasant: fatigue, irritability, and mild depression. The first dose of Interferon caused me to be up all night shaking and vomiting, but this immediate response rapidly subsided with later doses, over the first week or two. I injected myself with the Interferon three times a week at home.

69. I was able to continue working full-time most of the time. Blood tests showed that the virus responded to treatment during the course, but it was not sustained beyond the end of the course. Towards the end of the course, the virus started breaking through anyway and the dose was reduced because of the side effects.

70. I had no noticeable symptoms from HCV until about 1997 when I started noticing fatigue. This gradually got worse, until one day in November 2000 I was suddenly unable to continue working. I had to have a few days off. I was at work but suddenly just couldn't carry on. I went outside to a public phone to make a phone call to staff welfare in privacy. That call was really helpful and supportive and I was soon back at work. I knew from then on that I had to watch out for possible problems.

71. It seemed a good time to try to clear the virus again, before things got worse. In December 2000 I began another 24-week course of Interferon, this time combined with Ribavirin. I completed the treatment in June 2001.

72. The side effects were slightly worse than with the Interferon alone. Again the initial shaking and vomiting followed. Longer term I suffered

with fatigue, irritability, depression and feeling of being unwell. This was also accompanied by anaemia caused by the Ribavirin (my haemoglobin was down from 15 to 10 in the first few weeks). I was only able to work intermittently and with reduced hours.

73. Again, there was an encouraging response during treatment, but again it was not sustained more than a few weeks after the course finished. I had a glorious month after the treatment finished, when I felt well and I took up cycling. I then started to feel unwell again, and in October 2001 it was confirmed that I was still HCV positive.

74. I didn't work full-time from 2000. I cut down my hours to 32 per week, then 28 then 20. For the last three or four years my work performances had been definitely below par, which was most frustrating and upsetting for me, and clearly unhelpful for my colleagues too.

75. After a good spell in July and August 2006, by November it had become impossible to keep up the effort required for 20 hours per week, without fairly frequent absences. From January 2007 I was off sick, so asked for and eventually got early retirement on ill-health grounds. My retirement date was backdated to January 2008, when I was aged 51.

76. My pension and lump sum was not actually paid until October 2008, because of frustrating and unnecessary administrative delays by my employer, the GRO-B

77. The occupational health adviser was helpful and made a quick and favourable decision, but the delays on either side of this seemed interminable at the time. It gave us an anxious time financially, because my pay halved in July 2007 and stopped altogether in January 2008.

78. We had spent all our savings and run up an overdraft of nearly £10,000 by the time my retirement pay came through.

79. In September 2007 I tried the treatment again, initially for six months. I was on the maximum dose of Interferon and Ribavirin, and this time it was pegylated Interferon, which is slow release and only needs injecting once a week.

80. Side effects were similar but slightly more than the previous course. I was prescribed anti-depressants, which I was reluctant to take, but think helped a bit. I was quick to start reducing, and then come off the anti-depressants as soon as the course finished.

81. During treatment I was counting the weeks and it was a struggle. As well as not feeling well, I felt at risk of blowing up with anger and frustration at small provocation. I did not trust myself to stay calm and

reasonable. I thus tried to avoid getting into any such risky situation as far as I could. At that time two of our children were at university but the two teenagers were at home. My wife thus had to handle parenting issues, as well as coping with me.

82. At the end of 24 weeks Dr Makris advised carrying on with the treatment, as new evidence was coming out that longer courses were more effective. I gritted my teeth and decided to carry on with the treatment. After 36 weeks we had all had enough. As far as I could see, the research did not seem to show that extending it further would add much to the chances of success. At that point I stopped, in consultation with the haemophilia centre. This time the virus was cleared and remained clear and from then on I felt very much better in health.

83. I have not been aware of any difficulties or obstacles in receiving suitable treatment or of being denied any treatment that would have been helpful.

84. I have not faced any stigma as a result of my infected status.

85. My hobbies and out of work activities were affected in a similar way to work between 2000 and 2008. The main symptoms were variable but included fatigue, lack of concentration, memory, energy, motivation to get down to things ("brain fog"), and sometimes irritability.

86. I could sometimes work or concentrate quite well, but then tire easily, maybe in an hour or two. If I tried to press on with something, I then felt bad for a day or two.

87. Sleep was sometimes disturbed and I would wake damp with sweat. I often had mild discomfort, below the ribs on the right hand side and sometimes indigestion, mild nausea or dizziness.

88. Although I applied all my skill to managing the condition as best I could, it still remained unpredictable day to day, and week to week. In my view the effects had developed to a degree, which was not compatible with holding down a paid job even part-time. Not without creating disappointment, failure and frustration for myself, and corresponding problems for my colleagues.

89. I was unable to take part in out of work activities such as attending church meetings that I would normally attend in the evening, due to my tiredness. I was also involved in singing and would sing solos at music festivals about three times a year. These things had to be progressively cut back during the 2000-2008 period.

90. As I mentioned, our older two children were already at or past university stage while I was suffering the most. I do not think they were seriously affected by it.

91. Our younger son was still at home. I regretted not being able to support him as I would have liked during his teenage years, but he seems to be doing well.

92. I have similar regrets with regard to our younger daughter. She is happily married, but has had quite serious mental health problems in the last two years. I have to wonder whether my health problems in her teenage years might have had an effect on her. She is making good progress.

93. All our family relationships have been and remain very good.

94. After my retirement and subsequent clearing of the virus, I was able to resume many activities I had been forced to give up and take up new ones. I was able to look after the home and reduce the backlog of jobs, which had accumulated during my illness. These included voluntary work for the church and the GRO-B singing, training as a volunteer at the Citizens Advice Bureau in GRO-B and tutoring an A-level maths student from home. I was also able to help my younger son with his studies - maths and physics A-levels, and later physics at GRO-B University. This was an excellent contribution to revitalising our relationship, after what had to be a rather dormant period.

95. When I finished work in January 2007 my pay continued until July, then went down to half until January 2008 when it ceased altogether. My pension is now obviously a lot less than it would have been, although it is a good pension. It was based on about twenty years full-time work and eight years part-time. Being ill-health related it was not reduced for being paid early, though it was lower than it would have been at normal retirement because (i) my contributions reduced between 2000 and 2007 while I was part-time and (ii) then stopped at age 51 when I retired, and (iii) my salary did not increase in my later years of working life as it might have done. There was no enhancement for these missed contributions.

96. By 2010, two of our children had been through university, one was still at university and the other was 16 and likely to go. Even though my wife had increased her working hours to four days a week, this was a big financial drain and we had to spend out of my retirement lump sum so that the two younger children were not disadvantaged relative to the older two. Our elder daughter was also back living with us after graduation. Although our financial position was not stable we were, and are, clearly much better off than many other affected families.

97. Partly because of financial pressures and because we felt a call to move to a disadvantaged part of the city, we moved to a cheaper house in 2010. After settling in I was able to set up GRO-B Foodbank in 2011. I managed it in a voluntary capacity, until we appointed a paid foodbank administrator in 2015. I continued to do

voluntary work with the foodbank and took up other activities such as becoming an active Church Trustee at the GRO-B and a home group leader.

98. My wife has since cut her hours to two days per week after our daughter's illness and plans to retire in 2019.

99. Over the last year or two, I feel I am beginning to feel a lack of energy and lack of motivation. This is similar to the sort of thing I experienced in the ten years before my retirement, 1998-2008. I will explain in more detail in the below paragraphs.

100. I often find it difficult to get going in the mornings. It can take 3 or 4 hours from waking while I gather myself together to make breakfast, shower and get dressed and start on the tasks that I want to do that day. Usually this has improved by 10.30am and I then wonder how it has got to that time. I then get on with what I planned to do, taking breaks. Prior to the late 1990's when these problems first started to arise, mornings were the time when I could best function and get work done.

101. I often have a lack of concentration, which I describe as "brain fog". This, together with tiredness, forced my ill-health retirement 2008. This improved when the virus was cleared later in 2008 but appears to have returned to some extent in the last three years or so.

102. I have always had an excellent memory but began to find I was forgetting things as the effects of the virus started to emerge in the late 1990s. One day in the late 1990s I asked one of my work team about a work issue and was astonished to be told that I had written about it a few weeks before. I have not fully regained my good memory and at the present time I consider it less sharp than it should be, particularly when my energy and concentration levels dip.

103. I am determined to get on with tasks, which I have set myself and if this proves impossible through tiredness I can become, frustrated and irritable.

104. I did suffer depression whilst on interferon (in 1994, 2000/1 and 2007/8), but not since. While I would not now describe myself as depressed, I rather lament that I tend to feel less easy-going than I used to be.

105. These effects are variable. Often if I have a relatively busy day then the following day I feel washed out and can find it hard to achieve much.

106. I do not have as much energy to get on with tasks, as I want to. This began in 1994 during the first round of Interferon, then again around 1998 and continued until the HCV was cleared in 2008, being

particularly bad during treatment. After the virus was cleared, I largely regained my energy for several years and felt much better.

107. As some of these effects have begun to re-emerge I am adjusting my activities fit better with the pattern of doing things when I feel able rather than taking on too many activities where I have to be functioning at a given time. I can often concentrate and work at a task for an hour or perhaps two and then I have to take a break. Sometimes I simply cannot stay awake and have to sleep in a chair for perhaps 45 minutes.

108. On Sundays my wife and I attend a two-hour church service then return home for lunch. Often our adult children come for lunch on a Sunday and I find that I have to sleep in the early afternoon when I really want to be talking to them. A similar pattern affects day-to-day activities such as voluntary work, housework, light work in the garden, walking, shopping, driving, hobbies. I can do them for a while and then must have a break.

109. Even when I was functioning better maybe four years ago I could carry a tray of food up or down a flight of stairs, then a second tray, then I had to take a break while others continued. I am getting older of course, but in my view I have less physical stamina than I consider normal, less than I used to have and less than I observe in others of my own age or older.

110. I often suffer from poor sleep. I can get to sleep easily enough but usually wake during the night – maybe 1, 2 or 3am and once awake I usually lie awake for two or three hours before sleeping again. It appears to me that this sleep pattern is connected to my fatigue and enforced naps during the day. Poor sleep tends to last for many weeks at a time with few or no good nights. Then I can have a run of weeks with mostly good sleep.

111. To the best of my knowledge I had none of these problems before I first started to feel the effects of HCV in about 1998.

Section 6. Treatment/Care/Support

112. I have not been aware of any difficulties or obstacles in receiving suitable treatment. Neither have I been denied any treatment, which would have been helpful. I have not faced any stigma as a result of my infected status.

113. The specialist nurses at the haemophilia centre are very approachable and really nice. I feel I can call them or drop in if I need advice or support, which is extremely valuable.

114. Through the Haemophilia Centre I also saw a psychologist a couple of times, while on interferon and ribavirin. I saw a social worker once in connection with my SCM application (see section 7 below).

115. I would like to record my appreciation for the high standard of care and kindness I receive from the Sheffield Haemophilia Centre.

Section 7. Financial Assistance

116. I received £20,000 from the Skipton Fund in August 2004.

117. In 2016 the Skipton Fund started paying me £250 per month, plus £500 winter fuel allowance.

118. In 2017 responsibility for these payments passed from the Skipton Fund to EIBSS, the England Infected Blood Support Scheme.

119. In March 2018 my monthly payment from EIBSS increased to £1,500 per month under the Special Category Mechanism. These payments were backdated to October 2017.

120. The Sheffield Haemophilia Centre helped me identify these sources of financial assistance and supported my applications for them.

121. In the case of the Skipton Fund payment of 2004, I think I had to sign some sort of agreement not to pursue legal action as a condition of receiving payment.

122. The lump sum payment of 2004 along with the monthly payment beginning in 2016, were dependent on the fact of my infection with HCV rather, than any specific effects it had had on me.

123. Applying to EIBSS for payment under the Special Category Mechanism was different, and rather off-putting. It appeared to require a very high level of illness to qualify for payment, and there was little indication how the decision would be taken as to whether to award the payment or not. I read the information I was sent by EIBSS and I decided not to apply.

124. I later changed my mind after receiving a phone call from a specialist nurse at the Haemophilia Centre to ask me whether I had applied yet. She advised that I should. After the conversation, I decided that it was not right to rule myself out but that I should make the effort to apply and describe my health problems as best I could and leave it up to EIBSS to make the decision.

125. The Haemophilia Centre arranged for me to have an appointment with the specialist nurse and a social worker, to assist with completing the form. It was quite hard work to rake up the difficult days of 1998-2008, which I had moved on from. I did realise after completing the form that

some of the health issues, which I experienced ten years ago, seemed recently to be coming back to a degree.

126. Professor Makris, director of the haemophilia centre, endorsed my SCM application but I was still rather surprised when I was granted the extra payment.

Section 8. Other Issues

127. As mentioned previously, I requested medical notes from NHS trusts where I have been treated. There must be over 2000 pages, including some minor overlap. There are also some omissions where records cannot be found. I will make these available to the Inquiry if required.

Statement of Truth

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

Signed GRO-B

Dated 1st March 2019