Witness name: GRO-B
Statement No: WITN2059001
Exhibits: WITN2059002-16
Dated: 26 November 2018

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

Section 1: Introduction

1. My name is GRO-B. My date of birth and address are known to the Inquiry. I live with two of my grandchildren and have a loving family, who do look after me.

2. I was diagnosed with HCV in 2014, and was infected as a result of a blood transfusion I received in 1984. I therefore was infected for <u>thirty years</u> without any knowledge of it.

3. Until 17 July 2014, around when I was diagnosed with Hepatitis C ("HCV"), I worked as a support worker on a surgical ward GRO-B GRO-B. I was also an infection control nurse on the ward. I had to give up my job when I was diagnosed with, and started treatment, for HCV. I now live what I would describe as a lonely life, as most of my friends were work colleagues and I have nothing to do with them since finishing work due to my illness. I loved my job very much and I do miss it.

4. I make this statement in response to the questions set out in a "Rule 9 Request" letter dated 5 November 2018 sent to me by the Inquiry care of my solicitors, GRO-B. Those question headings are set out below, followed by my responses to them. Save where I state otherwise, the facts and matters set out below are within my own knowledge and are true. Where I refer to

matters that are not within my own knowledge, they are derived from the sources stated and are true to the best of my knowledge and belief.

5. I enclose an index which sets out the key supporting documents exhibited to this statement with their corresponding Exhibit Numbers.

Section 2: How infected

6. To the best of my knowledge I was infected with HCV at the Northern General Hospital on 14 June 1984 as a result of a blood transfusion ("the transfusion"). I received this transfusion after an operation on 13 June 1984 to remove a cyst. I had been rushed into hospital with stomach problems, which turned out to be a cyst on one of my ovaries. The cyst burst and caused internal bleeding, so I had an operation to remove it. After the operation I needed a blood transfusion as my stitches opened and I lost quite a lot of blood. I vaguely remember being in bed after the operation and feeling wet and sticky, which I presume was the feeling of the blood that I had lost, although I was what I would describe as "out of it" at the time. I can remember lots of people around my bed.

7. I exhibit medical records demonstrating that I had this operation and that I was given 3 litres of blood in a transfusion on 14 June 1984 (batch no. 129995) at approximately 11:45 [**WITN2059002**].

8. It is only possible to see that I had a blood transfusion from some very limited comments in my medical records from the time of the operation. A letter from my consultant to my GP at the time dated 27 June 1984 does not reference my blood transfusion [**WITN2059003**] and only states that:

> *"Unfortunately* **GRO-B** *wound leaked rather badly and she required a further G.A. [general anaesthesia] on 14th June for resuturing of superficial layers of her abdomen. Her further post operative course was uneventful…"*

9. In terms of the information or advice that was given to me at the point of my blood transfusion, I received no information about any possible risk of infection from a blood transfusion at any point. I was told after the operation that I had been given a blood transfusion because I had lost a lot of blood but nobody told me if this was emergency treatment to save my life, and nobody spoke to me about any possible risks.

10. I thought no more about the operation to remove my cyst and the blood transfusion until years later. Indeed, I was completely unaware that I had contracted HCV until June 2014, which meant that thirty years passed during which I was infected without my knowledge.

11. Throughout the years since the transfusion in 1984, I have suffered with various illnesses, especially stomach pains (please see section 5 on "impact" below for more details), and have been on different forms of pain relief for many decades. However, nobody ever did any tests or investigated whether the cause of my medical conditions may have been HCV.

12. In approximately 2013 I started to get severe nose bleeds and it was at this point, when my treating clinicians were investigating the cause of my nose bleeds, that they discovered that I had HCV (I append as **[WITN2059004]** a letter dated 13 December 2013 from my clinician at the Royal Hallamshire Hospital where I was being treated to my GP, which demonstrates that at this point I was diagnosed with anaemia and deranged Liver Function Tests ("LFTs")). By this stage as the letter demonstrates I had worsening fatigue that made me so tired that I was off work due to tiredness and needed to sleep during the day. At this point the hospital did some blood tests.

13. The next thing I knew I had an appointment to go to the Hepatology clinic. I did not know why I had this appointment, and I thought it was something to do with all the blood that I had lost from my nose bleeds. Nobody told me what the blood tests were for.

14. The clinician in the hospital who told me that I had HCV was very sympathetic to me as she told me the news. Once I started having investigations, I am under the impression that my treating clinicians knew straight away that I had HCV. The doctor explained the risks of others being infected and I was advised that my children should have a test to make sure that I had not passed it onto them (I had pregnancies in 1987, 1989 and 1990, following the transfusion. I also have 11 grandchildren.) I append as **[WITN2059005]** a letter dated 16 April 2014 from Dr V Gordon, a clinical research fellow in the Liver Unit at Royal Hallamshire Hospital, to my GP, which sets out my new diagnosis of HCV. I also append as **[WITN2059006]** a letter dated 23 May 2014 from Dr G Beejooa, a specialist registrar in Hepatology at the Royal Hallamshire Hospital, to my GP, which sets out my new diagnosis of HCV and says that I do "*not have any obvious risk factors for hepatitis C other than a blood transfusion at the Northern General Hospital in the 1980s following surgery for an ovarian cyst*".

15. Once I found out that I had HCV it took me a few days to come out of the shock. I have never taken drugs, and I have only drunk occasionally over my lifetime and when I was about 50 years old (so in approximately 2004) I stopped drinking altogether. I have only ever had sexual intercourse with my husband.

16. In my view it was the specialist liver nurse who I subsequently started going to see in the Royal Hallamshire Hospital who was the one that really gave me all the necessary information about my condition. She was very good to me and she always explained everything to me in such a way that I could understand. She never left me in the dark about anything.

17. That specialist liver nurse was the person who explained to me the history and background of contaminated blood being used for transfusions in the NHS. She also went through all my notes to pinpoint exactly when I had had the blood transfusion, in order to help me with my application for financial assistance from the Skipton Fund. She got in touch with the Skipton Fund on

my behalf and provided all the evidence that was needed to verify how I got HCV. Within a few weeks I was receiving payments and only a few weeks later the same nurse put in an application for me to get the Stage 2 payments because I had progressed to cirrhosis of the liver in that time. I append to my statement as [**WITN2059007**] a letter from my consultant hepatologist, Dr M A Karajeh, sent to the Skipton Fund on 15 January 2015 supporting my application for an additional payment. In this letter Dr Karajeh explains that my HCV is thought to have been acquired in the 1980s following a blood transfusion and they also give their opinion that I developed liver cirrhosis secondary to hepatitis C (as I have no other identifiable risk factors for chronic liver disease). I also append as [**WITN2059008**] a letter in response from the Skipton Fund dated 19 February 2015 confirming that as well as the £50,000 additional payment I had recently been paid at that point I was entitled to a regular annual payment totalling £24,574 for that year.

18. I am content with the level of advice that was given at the time of my diagnosis and that it was adequate. However, I do have extremely strong views about *when* my diagnosis should have been made and about the fact that I was only informed that I had HCV in 2014, 30 years after my transfusion. I am very, very angry about it. It should have been discovered a long time ago. Since 1984, I had another three children and I went into hospital for treatment for endometriosis (in approximately 1993), and had numerous blood tests and investigations for other conditions (which may be related to my HCV, although I cannot say for sure as I have not been told). Therefore, I simply cannot understand how HCV was never picked up in all this time. It makes me really upset and mad. It could have saved me a lot if I had known about this illness. To have it for 30 years and to not know what it is doing to your liver is intolerable. I would love to go into a room with the NHS and scream and shout at them about what they have done to me. I would love to give them a piece of my mind, but I recognise that it is 30 years too late. I have worked in a hospital setting for many years as a support worker and infection control nurse and I have never heard anything as awful as this. I am

angry and upset but I know I have to move past it all, particularly as I do not know who to blame; I cannot say, “it was him” or, “it was her”.

Section 3: Other Infections

19. I am not aware of any other infection caused by the blood transfusion. I am not HIV infected nor have I contracted HBV.

Section 4: Consent

20. It is my firm view that I did not give my informed consent for the blood transfusion in 1984 that was the cause of my infection. I was not made aware at any point of the material risks of the transfusion or that the blood might be infected, including with HCV. I certainly would have attached great significance to the risks if I had known of them. I was not informed at any point if there was any reasonable alternative course of treatment, if indeed there was one.

21. I honestly do not know if I was treated or tested at any point for the purposes of research but one thing does stick out in my mind – I have had numerous blood tests since 1984, but how come my HCV was not formally diagnosed until 2014?

Section 5: Impact

22. I have suffered so much health-wise both before and after 2014 when I was diagnosed with HCV. I have been in and out of hospital over the last few decades and I now have cirrhosis of the liver, ischaemic heart disease, hypertension, osteoarthritis, angina and depression. I do not know to what extent some of my health conditions are caused by HCV, although I expect some of them are (I do not include cirrhosis of the liver in this assessment because, as stated above, my doctors have concluded there are no other risk factors apart from the HCV).

23. One of the main conditions resulting from my HCV infection is cirrhosis of the liver, which has been expressly linked by my doctors to the HCV. Even though I have now been cleared of the HCV (see below), my liver is still getting worse. I am not on any treatment for this cirrhosis. I just go every six months for a scan and some blood tests. My liver nurse told me around the time of my diagnosis in 2014 that, if the worst came to the worst, I would have to go on the waiting list for a liver transplant. However, nobody has mentioned anything to me about this since.

24. I have been diagnosed with depression as a result of my HCV diagnosis. I think I may have always had a tendency to depression, but nothing like I have now. Since I had my first set of treatment for HCV (see details below) it has got a lot worse. My depression has taken everything out of me. I cannot walk for being scared of meeting people. This makes me very sad because I have always been the life and soul of the party, and now I do not go out at all. I am very lonely. I am grateful for having my grandchildren, two of whom live with me and the rest of which I look after for periods, but I would really like to have friends.

25. As a result of my heart-related health conditions, I went through a phase approximately three years ago where I repeatedly suffered from supraventricular tachycardia ("SVT"), where your heart beats much faster than normal. This was very scary as it kept happening to me, even when I was sitting down reading for example. I felt like I was dying. I kept having to go to A&E every time I had SVT to get my heart rate down. This culminated in an incident in November 2015 when I actually went into SVT while I was on the table during a coronary angiogram procedure. This was terminated by 6mg of Adenosine. I exhibit a letter from my consultant cardiologist to my GP confirming this incident as [**WITN2059009**].

26. One condition that I have suffered from a lot is stomach pains. It was, approximately, in the early 2000s when I first went to my doctors about this pain, which was not subsiding. They asked me to have blood tests done,

which I did. In 2008 I was referred to a consultant surgeon in the General/Gallstone Clinic at the Royal Hallamshire Hospital. At this point, a letter from the consultant surgeon to my GP (which I exhibit as [**WITN2059010**]) records that:

> *"For the last few years she has been complaining of right upper quadrant pain, which she describes as sharp, intermittent pain, not related to food and no obstructive symptoms. I note that you have requested LFTs, which were deranged and an ultrasound scan showed multiple gallstones, but we do not have the results of these."*

27. After this on 3 September 2008 I had a laparoscopic cholecystectomy (i.e. a gallbladder removal) operation under general anaesthetic. However, this did not alleviate my pain and I still continued to have stomach pains thereafter. I also had further LFTs after this operation, but I do not know whether my LFTs went back to normal. I have to ask myself, whey did they not test me then for HCV, or even did they already know that I had HCV?

28. Another condition that I have suffered from, which may be related to the HCV (although I do not know and have not been told as such by my doctors) is osteoarthritis. I should point out, however, that had rheumatic fever when I was 12 years and I was told that I might suffer from rheumatoid arthritis as I got older (although I suffer from <u>osteo</u>arthritis).

29. I have suffered a lot from headaches, and limbs that have severely ached, although I presumed these were age-related, even though I was not particularly old at all. This started approximately in the 1980s. I have been taking various painkillers over the years for this pain, including tramadol, a very strong painkiller.

30. I have also suffered from anaemia, and I was given medication to deal with this.

31. In approximately 1993 I had an operation because of my endometriosis. Again, I am confused as to why no blood tests that may have been taken around the time of this operation did not alert anyone that I might have HCV.

32. Finally, I would like to add that I am currently experiencing another medical complication, which may or may not be related to my HCV. I keep falling for no apparent reason. I am constantly covered in bruises. This is something my doctors are currently investigating and I have been for some blood tests and an electrocardiogram ("ECG").

33. After my diagnosis in 2014 I was seen regularly in the nurse-led clinic in the Liver Unit in the Royal Hallamshire Hospital and I started treatment for my HCV on 8 July 2014. I was treated with a triple therapy which was intended to consist of a 48-week course of pegylated interferon 100mcg, Ribavirin 1gm and Telaprevir 1.125gm (please see exhibit [**WITN2059011**]). However, this treatment made me so poorly that I ended up in hospital because of vomiting and anaemia and, ultimately, they had to stop the treatment. It also appears that the initial triple therapy, at the stage it was stopped, did not appear to be working. A letter from my specialist liver nurse to my GP dated 26 August 2014 (exhibited as [**WITN2059012**]) notes that the hospital had stopped my HCV treatment a week prior to that "*as her hepatitis C viral load had risen at the six week stage following her low reading after 4 weeks of treatment. We stopped the treatment as [there] was a little chance of clearing the virus with the treatment. As you know she has recently been in hospital as she was having problems vomiting and was also significantly anaemic.*"

34. My treating clinicians informed me that there was a new form of treatment for HCV that was going to be available soon and that I might be eligible for it. In January 2016, that did indeed happen and I was commenced on a treatment regime including Ledipasvir, Sofosbuvir and Ribavirin for a period of 12 weeks (see letter referring to start of treatment exhibited as [**WITN2059013**]). I was also very ill on this treatment and had to go to hospital almost every week for blood transfusions because my blood count was so low. A letter dated 8 April

2016 from my specialist liver nurse to my GP at the end of the treatment (exhibited as [**WITN2059014**]) states: GRO-B *has been symptomatic throughout her treatment, with anaemia being her main problem. She has required six units of red blood cells in total throughout her treatment to maintain her haemoglobin."* This treatment did clear my HCV.

35. I have not found that I have had problems in accessing care for any other conditions because of HCV. When I was diagnosed in 2014, I had a word with my dentist, who was brilliant. He said not to worry at all. The only thing I have noticed is that when I am going to hospital or waiting to undergo any kind of medical procedure I always have to be the last one, at the back of the queue. I think this is because of policies relating to people with infections. This is not nice to experience, but I do understand the reasons for this, particularly because of my background working as an infection control nurse.

36. Since finding out that I had HCV, I have become a hermit. I felt as if everyone as looking at and talking about me. I never go out of the house. I have no social life at all now, that has all gone, apart from that I greatly value the time I spend with my grandchildren. The problem is that I am too tired and worn out, mentally and physically, and too scared of people. If I need to go out anywhere I get a taxi, but that is difficult for me to afford.

37. I have the loving support of my family but they have been greatly impacted by my illness. It is that bad that if I do not answer the phone they are on my doorstep. If there is an ambulance near my house, the neighbours phone my family. I really feel for them because of the worry they have.

38. One of the greatest personal impacts on me as result of being infected was that it forced me to give up my much loved job as a surgical support worker and infection control nurse on a surgical ward GRO-B GRO-B. I worked in the GRO-B for about twenty years but I had worked as a support worker for eight years prior to 17 July 2014 when I gave up my job. GRO-B.

39. It made me feel sick when I discovered that I had HCV, thinking that I could have put people in danger while I was doing my job. The only thing that kept me going was knowing that wearing gloves and taking safety precautions were essential to my job as infection control nurse and that I was a real stickler for cleanliness. I always had my gloves on and was always telling nurses to put theirs on if I saw them without. The only trouble is I did not know that I had an infection.

40. I had to give up my job because I was that poorly when I was having my first round of treatment for the HCV (see above for details of treatment). I was so ill that I went on sick leave. I was in and out of hospital and I lost my hair and teeth. I was on sick leave for a year. After I had the treatment, I knew I could not go back to my job. It required a 12-hour shift and it took me a long time to cross the road, let alone walk up and down the ward for 12 hours. The matron on my ward was brilliant. She said if I ever wanted to go back to work she could find me an office job. However, I did not want that. I loved working on those wards. Even now I still send Christmas cards to two of the patients I looked after. I desperately miss my job.

41. To this day, four years after I had to leave my job, I still feel very upset that I am not at work. I wish I could change the clocks back to 1984 and refuse the blood. I just wish things were different. I miss the people I met in the course of my job and I miss my colleagues, who were also my friends. Now, if I have to go into the hospital for any tests, I go in the back doors of the hospital because I do not want to see them. In fact, I am scared to see them. My HCV has made me very scared to see anybody.

42. Financially, my HCV has impacted greatly on my life. As stated above, I had a long-term and stable job as a surgical support worker on hospital wards. Since I had to give up my job to take early retirement I have struggled financially. I had not been in a pension scheme long enough to get any decent money. I rely on Employment Support Allowance mostly but I do struggle to

make ends meet as my rent is £98/week and then there are the multitude of other household bills to pay.

43. I would like to mention a very negative experience I had with the Department for Work and Pensions ("DWP") when I was applying for Personal Independence Payment ("PIP"). I applied and my application was rejected. I exercised my right to a mandatory reconsideration of the decision in my case and I felt like the response I received back was a really nasty letter that seemed to insinuate that there was nothing wrong with me. It made me feel like they thought that I had been lying. For example the letter stated that I was able to plan and follow the route of a journey unaided, safely and reliably for the majority of days but the truth is I am terrified to go out and will only get a taxi if I have to very occasionally. The fact is that I had carefully planned the trip to the assessment centre for many days and gave the taxi driver the address, but I had been worrying about this assessment for days. I told the DWP that I had received contaminated blood as a result of a transfusion. I append the mandatory reconsideration notice as **[WITN2059015]**.

44. I cannot even explain how I feel; my situation upsets me that much. I have always associated HCV with drug addicts, because of the way it is perceived and considered in society and large, and as a result it makes me feel dirty. I fully understand that it is me that feels like that. When people look at me, I presume that they are thinking negative things about me. Deep down I know they will not be but that is the impact of the stigma in society about HCV and those infected as alcoholics and drug users.

45. Health staff generally have been great apart from the odd one who tells me to stop drinking because it is making my illness worse. Presumably they have not read my notes properly and assume I am an alcoholic and that is the cause of my cirrhosis of the liver.

46. One incident does stick out in my mind in particular. I began to see a different liver nurse last year. As usual I had my liver checked and underwent blood

tests. My liver had got a bit worse the nurse called me up to tell me that the clinicians responsible for my care had had a multidisciplinary team meeting ("MDT") about my results. She was phoning to pass on their advice to me to stop drinking. I told her that I did not drink (at that point I was completely teetotal) and that I have never drunk much. I was very upset for days after this incident. Six months after that I did see my usual nurse and told her about this phone call. She said she would have a word with those involved and was extremely sympathetic. I think it was caused by the MDT not reading my notes properly and not comprehending that I had been diagnosed with HCV. I exhibit to this statement as [**WITN2059016**] a medical record of a letter sent by the specialist liver nurse to my GP, which I believe to the best of my knowledge references the phone call I describe above. This record states, *"I have advised* **GRO-B** *of the findings and taken the opportunity to clarify her alcohol intake. She denies any alcohol intake".*

Section 6: Treatment/Care/Support

47. Since I was diagnosed with HCV in 2014, the medical care from the Liver Unit in the Royal Hallamshire Hospital the has been absolutely brilliant.

48. No one has ever suggested to me that I could receive counselling. I also cannot remember any medical professional ever asking me if I need additional emotional support, including my GP. However, I should add that I would have been very unlikely to have accepted such support and I do not want counselling because I am an extremely private person and would find it difficult to talk openly about how I feel. I do not even talk to my GP about how I feel about my HCV diagnosis. It has been a significant challenge for me to share private information in order to give this witness statement.

Section 7: Financial Assistance

49. I have explained above how I obtained Skipton Fund payments with the assistance of my treating specialist liver nurse. I have nothing further to say except that I was satisfied with that process.

Section 8: Other Issues

50. I would like to make some further comments in this final section of my statement. Having HCV, both before and after my diagnosis, has impacted my life irreparably. As I said above, I used to be the life and soul of the party but now I am too scared to go outside. It has taken away my working life and my friends and social life. I have the support of my loving family and without them I do not know what I would do.

51. What I want from this inquiry is the truth. I want to know whether there was some kind of cover-up, why those responsible have not admitted to that if so, whether people like me were part of a research project or were used as "guinea pigs", and if that was why we had to wait until our livers were so damaged that they were irreparable before something was done about it. I expect the inquiry to uncover the truth.

Statement of Truth

I believe the facts stated in this written statement are true.

Signed:

GRO-B

Dated: 26 November 2018