Witness Name: GRO-B
Statement No.: WITN1987001
Exhibits: WITN1987002-WITN1987029
Dated: 11 October 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

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

2. My date of birth is GRO-B My address is known to the Inquiry. I have five children (four daughters and one son) and nine grandchildren and one great grandson. I used to work as an activities coordinator and am now retired on health grounds. I am divorced and live alone.

Section 2. How Infected

3. When I was pregnant with my fourth child I was admitted to GRO-B Maternity Hospital for a planned caesarean section in 1987. I had lost my previous baby at five days old following an abruption so it was decided that this delivery would be by caesarean. I became anaemic during the pregnancy and my haemoglobin levels were very low so some weeks before delivery they tried to transfuse me with iron. I had an allergic reaction to iron and they had to

stop. Instead, the hospital decided to give me a blood transfusion which took place on GRO-B 1987, the day before the planned caesarean. When the nurse was putting the transfusion up I asked her if the blood was ok, and she said yes, it was fine, and told me it had been treated with gamma rays. **WITN1987002** is the maternity notes from the delivery noting the blood transfusion. The next day my daughter was delivered by caesarean at around 11.30am. My fifth child, my youngest daughter, was born 18 months later.

4. I received no information or advice about the risk of being exposed to infection. As I have explained, the nurse in fact reassured me that the blood was safe because it had been treated.

5. As a result of being given contaminated blood I was infected with Hepatitis C (HCV).

6. I found out I had been infected with HCV when I was contacted through the Look Back programme in 1996. I received a letter from the programme and my GP made an appointment for me to go in. I met with two men from the Look Back programme at the GP surgery, and my GP joined us halfway through our meeting. They told me they had traced me and that I had been given contaminated blood. They advised me to get tested for HCV.

7. My doctor did the blood tests, confirmed I had HCV and referred me to a hepatologist at the GRO-B Hospital. The GP could tell me nothing about the virus and just said he would refer me. I knew nothing about HCV and did not know what was going on.

8. **WITN1987003** is a letter from the Look Back programme to my GP in April 1996 requesting a sample of my blood for testing for HCV. **WITN1987004** is a letter to my GP from December 1996 confirming a positive test for both HCV antibody and PCR. **WITN1987005** is the referral letter from my GP to the consultant in Infectious Diseases in January 1997.

9. When I saw the hepatologist he just did more blood tests. No one told me what HCV was or explained anything about the infection, I was just told I had the disease and that they would treat it. I was given no leaflets and had to read about HCV online to learn anything about it. I do not feel I was given adequate information to help me understand or manage the infection. I do feel I should have been given much more information much earlier. I was not told about the risk to others and had to find out for myself that my husband would have been at risk, as would my children.

10. **WITN1987006** is the letter from the Infectious Diseases consultant to my GP dated March 1997 noting, '4 caesarean sections circa 1970, 86, 87, 89, transfused on 4 occasions for anaemia in between the 1970-87 (the 1987 sample appears to be the one causing the infection) […] no other risk factors. Clinically she appeared well with no anaemia, jaundice, lymphadenopathy, fever nor rash nor chronic hepatic stigmata […]'. 'GRO-B is symptom free and the liver functions tests are entirely normal. It is likely that this is an asymptomatic carriage but it will be important to exclude sub-patent chronic inflammatory liver disease that might require immune modulation using Interferon.' I only had three caesarean sections, one in 1986, one in 1987 and one in 1989. I believe I did have four transfusions, so this information is correct.

11. **WITN1987007** is the medical report of my liver biopsy in 1997 confirming very mild chronic persistent hepatitis, 'probably acquired 1987 with transfusion'. A letter following the biopsy in May 1997 to my GP is at **WITN1987008** and confirms, 'no evidence of architectural distortion nor significant fibrosis; a very small degree of lobular inflammation and expansion of occasional portal tracts with lymphocytic infiltrate, but no piecemeal necrosis. The appearances were those of very mild chronic hepatitis with no evidence of fibrosis at this stage.'

Section 3. Other Infections

12. I do not know whether I have received any infection other than HCV as a result of being given infected blood. I do not know if I was tested for anything else when they tested me for HCV.

Section 4. Consent

13. I do not believe I have been treated without my knowledge or consent, or for the purposes of research.

Section 5. Impact

14. In the years when I was undiagnosed I suffered with tiredness, but I had a young family and put it down to that. I had a continuous cold for the last year or so before I was diagnosed and regularly suffered with flu like symptoms. I suffered a little with panicky feelings from time to time. I also suffered with upper abdominal pain for months on end in around 1994 and oesophagitis and a hiatus hernia was diagnosed in the same year. An ultrasound to investigate revealed multiple gall stones and I underwent a cholecystectomy in 1995 as a result. When I was diagnosed everything sort of fell into place and it explained why I had not been feeling myself for so long.

15. When I was told, I felt devastated. I could not tell anyone. I got depression. I thought a lot about telling my children and my wider family but could not: I became very fearful that they might stop me seeing my grandchildren.

16. Initially, in 1997, I was told treatment was not necessary. **WITN1987009** is a letter from my consultant to my GP noting, 'the hepatitis C carriage is not associated with any significant biochemical or histological disturbance and Interferon treatment was not indicated'.

17. During this time I can see from my medical records that the National Blood Service contacted my consultant regarding the national register of HCV infections. I was not told about this register and was not aware that my GP had been contacted about this. The first time I became aware of this was reading my medical records for the purposes of preparing this statement.. The initial letter from July 1998 is at **WITN1987010**. A patient information sheet is enclosed with this letter but I did not receive a copy of this information sheet from my GP.

18. In 1999 I was reviewed and **WITN1987011** is the letter to my GP following this review, noting no there was no significant clinical or biochemical evidence of inflammatory activity and therefore I would continue to be kept under surveillance.

19. **WITN1987012** is a letter from the HCV National Register of May 2001 requesting liver biopsy specimens from my consultant. I was not aware of this request. **WITN1987013** is the letter from my consultant to the Histopathology Department asking for the slides to be sent. Again, I was not aware of this.

20. **WITN1987014** is a letter from a clinic appointment in 2001 where the consultant says, 'she is well. Liver functions tests from the 24th May 2001 are entirely normal' [...] She is aware that she will need regular follow-up, and possible future anti-viral treatment should her liver function tests become abnormal in the future. Today we discussed the slight risks of transmission through blood spills, sex and mother to child transmission. She works as a GRO-B in a GRO-B and is not involved in any procedure or intervention that might put nursing home residents at risk. Her husband and 12 year old daughter have not been checked for hepatitis C infection (she is known to have acquired the infection 14 years ago), and she will consider having her daughter tested at some point in the future, although her husband has declined testing.' I do not recall this conversation with the consultant.

21. **WITN1987015** is a further letter from the HCV National Register in January 2003 to my consultant tracing my follow-up. In handwriting on the letter it says, 'Pam is this pt still coming to clinic', with a further handwritten note, 'This patient does not have any follow-up appts'. I think this means I was lost to follow up at this time.

22. I was received again in April 2003 and **WITN1987016** is the letter to my GP following this appointment noting that my LFTs were within normal limits and there were no stigmata of chronic liver disease. The letter also notes that the doctor completed the HCV National Register form with me. I do not recall this.. I was to continue to be monitored.

23. I was seen again in January 2004 and the letter at **WITN1987017** confirms that my LFTs were normal (after having some mildly abnormal ALT readings previously), and a repeat ultrasound was normal. The letter says, her 'hepatitis C (Genotype 1) which means that any treatment she would have would have to be for one year rather than six months with much more limited chance of success. However, she is essentially asymptomatic with normal liver enzymes and normal ultrasound. Realistically there is no indication to treat her with anti viral agents.' I was reviewed again in 2004 and 2005. In 2006 I had an ultrasound guided liver biopsy which showed mild chronic hepatitis C, fibrosis stage 1/6 and inflammatory grade 3.18 (**WITN1987018**). They decided not to start treatment as there had been little change in my biopsy results over the last seven years and my liver enzymes were normal.

24. During all of this time it is important to make clear that treatment options were not discussed with me and treatment was never agreed or not agreed: I was simply not offered it but instead told they would 'watch and wait'. The only time I was offered treatment was when I was simply told I was having it, and that was in 2010, at no time prior to this was treatment offered to me.

25. I was reviewed again in 2007 but then seemingly lost to follow-up for a few years as the letter to my GP from my consultant in June 2009 at **WITN1987019** notes, 'it is a couple of years since I have seen her which is disappointing as I

had planned to see her in a year when I last saw her two years ago. [...] in the past her biopsies have only shown mild inflammation and we have elected to adopt a wait and see approach. [...] We need to make a full assessment of her hepatitis C at this stage.'

26. **WITN1987020** is a letter from September 2009 following a further liver biopsy in July that year confirming that the hepatic inflammation had worsened but that I was not cirrhotic. The letter notes, 'I have discussed this with her at some length today and I think it probably time that we considered treatment her Hepatitis C which has not required treatment so far. I have explained to her that she probably requires 48 weeks of treatment with Interferon once weekly and Ribavirin twice daily with a 55 per cent chance of sustained response to treatment (this could be considered a cure) [...].'

27. **WITN1987021** is the liver biopsy report from July 2009 noting 'moderate chronic hepatitis with a mild lobular component, mild to moderate interface hepatitis and a hint of possible early bridging fibrosis'. The necro-inflammatory score was 6/18 and the staging score 2/6.

28. In 2009 I recall my results showed I had a very high viral load, millions and millions, so it was decided I would do the 48 week treatment, rather than 24 weeks. I received treatment with Interferon and Ribavirin. I did the treatment alone as I had told no one about the virus. I had to look after myself. I injected myself every week and took Ribavirin in tablet form. I knew from the moment I injected myself that I would not be able to move for three days or so, then I would feel a little better, and then it would start again the next week. Initially I went to hospital for check-ups each week, and then each month. I managed to complete the treatment because I felt I had no choice: I wanted to get rid of the virus and couldn't give up, although many times I felt like giving up as I couldn't take much more. **WITN1987022** is a letter from my consultant to my GP in October 2009, before I started treatment, noting that the side effects were explained to me (to include anaemia, lymphocytopenia, neutropenia, lethargy, depression, etc). These side effects were not explained to me: I was not

warned of any side effects at all. I was just told that I was having treatment and that was it.

29. During the treatment I struggled to get out of bed, I had fatigue, mouthfuls of ulcers, sores all over my body and nausea. I could not eat, lost weight and lost some of my hair. I felt very low during the treatment and suffered with depression and panic attacks. I would get panic attacks when I went shopping and have to come home and sit with the front door open as I couldn't bear being in a closed room. I had never felt that way before I started treatment. I have been on Citalopram for depression since the beginning of my treatment in 2010.

30. **WITN19187023** is a letter from my consultant to my GP 24 weeks into treatment. The letter confirms I was suffering with depressive symptoms and mouth ulcers. Although HCV RNA was at 12 weeks into treatment was undetectable it was decided I would continue with treatment as, as the letter notes, 'she is quite keen to maximise the chances of eradicating the virus completely'. I do not recall having a choice about this, I was simply told I would be having 48 weeks of treatment. I wasn't offered a reduced time of treatment.

31. I felt suicidal when on treatment and was referred for counselling via my GP. My husband had sexually abused me some years previously and I ended up leaving him and taking the children with me. During the treatment I felt very down and asked for help. I received the counselling some time after treatment finished. The counselling wasn't specifically for the HCV, it was more to do with everything that was going on in my life at the time, but it did help.

32. **WITN1987024** is an extract from my GP computerised record from this time, confirming I was suffering mentally, noting on 26 July 2010, 'panic attack, still struggling with her anxiety ss and poor sleep. Weened herself off the benzo. Medication: citalopram. [...] Agreed to increase citalopram, [...] add zopiclone.' On 6 September 2010 the same page notes, 'multiple painful mouth ulcers,

since she started on treatment for Hep C she says she is receiving at the hospital. Also wanting something for pain, as since she started on treatment she's been having generalised pains and aches, paracetamol not helping much.'

33. In 2011 I was told I was clear of the virus (**WITN1987025** letter from my consultant to my GP in April 2011) and discharged to the care of my GP.

34. I felt very unwell a few years ago, with pain in my abdomen and chest, and went to my GP as I thought the virus had come. Although my GP said it wouldn't have, he agreed to refer me back to my consultant at the hospital back (**WITN1987026** is the referral letter). The consultant did the test, and it showed as still clear. I don't know why I felt like I did, I think it was just the symptoms of the treatment.

35. I do not receive any follow-up care. I can feel I am getting worse and worse. I still suffer with fatigue and frequently cannot think straight or find the right word (**WITN1987027** is a letter from 2011 confirming I was still suffering with occasional sweats, lethargy and malaise). I suffer with brain fog, anxiety, depression and panic attacks. I now also itch all of the time. I have a pain in my side under my ribs where my liver is and can only relieve it be lying down. I want to have another scan because I want to know how my liver is. I want to know if things have got worse and whether I have cirrhosis now. However, I am now frightened to go back to my GP to ask for a scan because I was made to feel stupid when I asked for a blood test last time when I thought the virus had come back. Now I am 'clear' I worry I will be fobbed off and sent away. It would also take months for any referral to come through. If I had the money I would pay privately for a scan for myself so that I am not made to feel stupid and don't have to wait so long.

36. I went to one of the Inquiry meetings in Manchester in February 2019. It is only half an hour by train and the meeting was an hour and a half but I had to

leave early to come home because I was wiped out. I desperately wanted to go but it was too much for me. When I got home I had to crawl up the stairs because I could not walk: my legs were swollen and my joints were aching.

37. I faced considerable delay in accessing treatment. After my first appointment with the hepatologist the hospital said they would contact me to start treatment. I heard nothing for a year, so called the hospital and they said they would look into it. It seemed as if they had forgotten about me. After that I was started on treatment straightaway. I was told that Interferon and Ribavirin was the only treatment option available: there was nothing else.

38. I did not think my HCV status had impacted on my treatment and care for other conditions, however, my medical notes contain records from when I underwent an oesophago-gastro duodenoscopy in 2007. Written by hand and highlighted on the notes of the care plan for the operation is 'HEP C END OF LIST' (**WITN1987028**). I was unaware of this until I found it in my notes.

39. No one knows about my diagnosis with HCV so I have to do most things for myself. I have a car and can get myself to the shops. I used to love shopping and would go with my daughters for day trips. Now I can only manage to get to get to the shop, buy what I need and come straight home. I find I can do less and less now and just tell my family it is because I am getting older. One of my daughters comes over to help me with the housework.

40. I do as much as I can as a grandmother, and will always try to look after the grandchildren to help my children out. However, I cannot look after the very young ones, as I cannot be on my feet all day looking after them and I cannot pick them up or change nappies. Often I do not have the energy to help but I push myself to do it, even though I would prefer just to sit at home on the sofa and rest. I would love to be able to play a more active role in my grandchildren's life.

41. The virus has had a great impact on my life, including my private family and social life. I have told no one as I am afraid of being stigmatised and I do not know how people, including my family, would react. My family is everything to me: I was brought up in care, after my brother and I were taken away from our mother when she could no longer cope with us. When I was a child in care I was subjected to sexual, physical and emotional abuse. My children and grandchildren are my life and I would never do anything to risk that. Even though I am clear of the virus I still feel stigmatised. Even though I know I am safe I would feel like I couldn't be near my grandchildren. I have chosen not to have a partner as I would not want to tell him about my past infection with the disease.

42. I worked in a care environment for years without knowing I had the virus. When I found out I was shocked: I had been delivering personal care for many years and was horrified that I might have passed the virus on to others. I was very careful, and I don't remember a time when I ever did anything where I could have infected someone, but it doesn't stop me from thinking about it and worrying.

43. The virus has impacted on my employment and my finances because when I was diagnosed I had to tell my employer. I continued to work until I started treatment but then I found was never well enough to go back. **WITN1987029** is a letter from my consultant to my GP 18 months after treatment ended, in September 2009, confirming that, 'She has not been able to work for the last year since finishing treatment, as she wasn't able to keep with the pace of her job working as a volunteer co-ordinator'. I retired on health grounds just before I turned 60, but had expected to work until age 65. I loved my job, they were like family and it was terrible being forced to leave and not being able to tell my colleagues why.

Section 6. Treatment/Care/Support

44. I have never been offered counselling or psychological support in consequence of being infected with HCV. I tried to ask but nothing came of it. In the past I have just tried to forget about the virus, but now because of the Inquiry I have to face it all over again which is really painful. I was referred to Healthy Minds in 2012. after I asked the doctor for help and this is what he offered. I had to wait a year to receive this counselling but it did help a little.

Section 7. Financial Assistance

45. I found out about the Skipton Fund when someone at a support group told me about it. I received the £20,000 Stage 1 payment in around 2010. I have also received financial assistance through the Caxton Fund. I receive the winter fuel payment and I am also in receipt of benefits, including PIP, ESA and Universal Credit. I now also receive the Stage 2 monthly payments of £1,500 from the EIBSS and the top up payment of £360 per month.

46. The process of applying for financial assistance is very difficult. I rely on my car very heavily and cannot get around without it. When it broke down I had to get a new part and the Caxton Fund required three quotes. The part was £50 and in the end I just had to pay for it myself as I could not go for weeks and weeks without a car whilst waiting for approval from the Fund. You feel like you are begging.

47. The financial assistance I receive is not really enough. I would not be able to afford to live without the extra £1,500 I now receive. Once I have paid my rent and bills there is not much left.

Section 8. Other Issues

48. I hope the Inquiry will ensure that something like this never happens again to anybody else. I hope too that those responsible are held to account.

Statement of Truth

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

Signed

GRO-B

Dated 11 October 2019