Witness Name: GRO-B
Statement No: WITN3518001
Exhibits: WITN3518002-06
Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B of GRO-B GRO-B My date of birth is GRO-B

2. At the time I was treated with infected blood and up until 1991, my name was GRO-B. In GRO-B I changed my name to GRO-B I have attached to this statement marked Exhibit WITN3518002 a copy of my Deed of Change of Name dated GRO-B

3. I live alone in a rented cottage in GRO-B and have been here for 13 years. I am retired.

4. I have two sons aged GRO-B and GRO-B My middle son passed away when he was only GRO-B

5. I was infected with Hepatitis C as a result of receiving contaminated blood products.

6. This witness statement has been prepared without the benefit of access to my full medical records. In so far as I have been provided with limited medical records, I have referred to relevant entries within this statement.

7. A few years ago, I requested copies of my records from Addenbrooke's Hospital where I was treated with infected blood. They informed me that my records have been destroyed.

Section 2. How infected

8. On GRO-B I went into labour and was admitted into the maternity department at Addenbrooke's Hospital in Cambridgeshire. This was my third pregnancy and there were no complications with the birth. I remained in the ward for a while, although I do not recall the exact length of my admission. During my time there, I requested a bed pan from the nurse as I needed to urinate but did not feel well enough to get up. The nurse was very unsympathetic and told me that I did not need a bed pan and could make it to the toilet myself. I was feeling extremely weak and dizzy, but got out of bed, following which I collapsed on the floor and started haemorrhaging.

9. I was lying in a pool of blood on the floor and another patient on the ward rang the nurse to inform her of what had happened to me. After that I was only semi conscious of my surroundings, and cannot remember much of what happened. I remember feeling panic and being aware of panic all around me from the nurses and doctors. When I came to I was connected to two drips, one of which was a blood transfusion. I do not know how much blood I received.

10. I do not believe I was told that I was getting a transfusion, but even if I had, I was probably not in a position to absorb that information. I was very weak and unwell at the time. I was not given any information about the risk of infection from the blood transfusion by the hospital.

11. I was infected with Hepatitis C as a result of the blood transfusion I received at Addenbrooke's Hospital in GRO-B

12. For many years I was feeling extremely unwell, getting infection after infection and feeling very tired. I knew that there was an underlying cause, but the doctors were not really getting to the bottom of it.

13. In 2007 I found out that my ex boyfriend from 1989 was ill and that he had Hepatitis C. I went to my GP to request a test for Hepatitis C in 2007. I had been told that you don't tend to get Hepatitis C through sex but I found that hard to believe and I was worried that I might have been infected.

14. I was tested and the result was positive. When my GP told me that I had Hepatitis C in September 2007, I was in shock. Even though I'd had an inkling that I might have the infection, I was still not prepared for the news. I attach to this statement marked WITN3518003 copies of the test results dated 17 August 2007 and 5 September 2007.

15. Mr GP did not give me any information about the virus during that consultation. I was not given adequate or full information to help me manage or understand the infection. My GP mentioned a Hepatitis C Trust and also referred me to the Yeovil District Hospital in Somerset (YDH).

16. I contacted the Hepatitis Trust and they gave me a lot of information on the virus. I also purchased a book on the virus which I read thoroughly. I taught myself about the virus and its implications. I knew that I should not share my towels or toothbrushes and that if I bled, I should sterilise anything I had been in contact with.

17. I was also given information about the virus by the YDH who treated me for Hepatitis C.

18. I have attached to this statement, marked WITN3518004, my GP's referral letter to the YDH dated 7 September 2007. This letter makes mention of my ex boyfriend contracting Hepatitis C and the fact that I had a blood transfusion

in 1979. The letter also notes that I had used intravenous drugs in the past, in the 1960s.

19. I contacted my ex partner, who has since passed away, and I found out that he had a different genotype of Hepatitis C. As we had different genotypes, I could not therefore have caught the infection from him.

20. For a short period when I was 23 years old, I experimented with intravenous drug use. I was working in the music business as a personal assistant, hence the availability. I confirm I never used shared needles.

21. I realised that the only explanation for the virus was the blood transfusion I had in GRO-B When I was having treatment at YDH, the main nurse said to me that she believed I had contracted the infection from contaminated blood.

Section 3. Other Infections

22. Other than Hepatitis C, I have not received any other infections.

Section 4. Consent

23. As far as I am aware, I do not believe that I was tested without my knowledge or consent.

24. In relation to the blood transfusion, it is hard to say whether or not I was treated without my consent. I was weak and woolly at the time and cannot recall anything that was said to me. Even if anything was said to me at the time I doubt I would have taken it in.

25. I do not believe I was given adequate or full information at the time of the blood transfusion.

26. I do not believe that I was tested or treated for the purposes of research.

Section 5. Impact of the Infection

27. Not long after I was diagnosed with Hepatitis C, I suffered from major depression for which I received treatment and was assigned a Community Psychiatric Nurse. When I was 18 or 19 I had suffered from similar depression, but I overcame it and did not have any further problems with depression until 2007. Knowing that I had the infection made me feel like a pariah and unclean. I felt obliged to contact my ex partners to inform them just in case I had passed on the infection. My children were also tested. Thankfully, all persons tested were clear of the virus.

28. Because of the Hepatitis C infection, my immune system has been compromised and I am extremely susceptible to any colds or infections. I currently suffer from Meniere's disease, diverticulitis, fatigue, chronic headaches, brain fog, apathy and extreme tiredness. I am also hyper sensitive to all kinds of medication.

29. I was treated for Hepatitis C at YDH. I also received treatment at the GRO-B Hospital.

30. When I was initially diagnosed my consultant at YDH offered to treat my Hepatitis C infection with a drug called Interferon. I refused this treatment as I thought it would worsen my depression. I was told to go on antidepressants, but I was reluctant as I would have to take far too many drugs. As I have mentioned, I am hyper sensitive to drugs and this also influenced my decision to refuse Hepatitis C treatment at the time.

31. In 2008 I had a liver biopsy which showed that I had mild fibrosis.

32. In 2012, I was offered another liver biopsy in order to check if I had cirrhosis of the liver and to check if my liver had changed significantly since 2008. I refused as it was too hard on my body and I felt it was very invasive. I was okay after the first biopsy, but I did not want to do it again.

33. In 2015 I had a fibroscan which showed that I did not have hepatic fibrosis.

34. I had my first treatment for Hepatitis C in February 2017. The treatment involved four drugs: Dasabuvir; Ombitasvir; Paritaprevir; and Ritonavir (Viekira Pak). At the start of that treatment I had a very high viral load. The treatment commenced on 20 February 2017 and initially seemed to be working, but on 7 March 2017 it started failing. I was then prescribed with Ribavirin as well as the other four drugs.

35. Unfortunately the treatment was unsuccessful and on 20 April 2017 the treatment was stopped due to non response. I found out later that the treatment was unsuccessful because I was treated for the wrong genotype - genotype 1b instead of my correct genotype of 2b.

36. As my first treatment for Hepatitis was unsuccessful, I was told that I would have to wait until alternative treatments became available.

37. On 28 February 2018, I was going through my letters from the hospital and discovered that the information about my genotype was inconsistent. In 2008 I had been told that my Hepatitis C infection was genotype 2b. In correspondence from the hospital between 2010 and 2012, my genotype was stated to be 1b. In correspondence dated 2014 I was genotype 2b, however in a letter dated 2015, I was genotype 1b again. In 2016, I was stated to be genotype 2b.

38. Alarmed, I confronted the hospital about it and demanded a re-test. My genotype was confirmed to be 2b which proved I had been given the wrong treatment – I was treated for genotype 1b. I was distraught. The fact that I had to point it out to the hospital made it worse for me. It was probably a typing error but it was vital information which they couldn't afford to get wrong. This caused me so much grief.

39. In October 2018 I started treatment for Hepatitis C a second time. This time I was treated with Vosevi. At the beginning of the treatment my viral load was 800,000,000, but on 13 February 2019 I was told that my viral load was non

detectable. I have one blood test due at the end of 2019 to confirm the success of the treatment.

40. The most alarming side effect of both treatments I received for Hepatitis C was an intensely itchy rash which I was unable to cope with and which caused me to suffer from insomnia. The rash started around the time that I started my first treatment for Hepatitis C and continued after my treatment stopped. I was referred to the dermatology department at YDH twice in relation to this condition.

41. On 16 May 2018, I was given a skin biopsy to find out the cause of the rash on my skin and the doctor believed it was either Gianotti Crosti Syndrome or Grover's Disease. I was told that both conditions are attributable to antiviral medications.

42. I suffered from chronic fatigue while undergoing treatment for Hepatitis C. Mentally, I suffered from depression and I felt completely hopeless. These feelings of hopelessness were exacerbated by the fact that the first treatment was unsuccessful.

43. I have attached to this statement marked WITN3518005 an extract from a printout of my GP records which contain:

    a. A record of my GP consultations in July, August and September 2007 when I first tested positive for Hepatitis C (pages 3-4);
    b. An entry dated 19 March 2008 which confirms that I had mild hepatic fibrosis (page 2);
    c. An entry dated 8 October 2018 which confirms that I was treated for genotype 1b instead of 2b (page 1).

44. I have attached to this statement marked WITN3518006 copies of the following :

a. Letter from YDH dated 15 November 2007 following my first appointment and documenting my concerns about Interferon treatment. This letter states that I have Hepatitis C genotype 2b;

b. Letter from YDH dated 19 March 2008 confirming that my liver biopsy showed mild fibrosis and mild hepatitis. This letter states that I have Hepatitis C genotype 2b;

c. Letter from YDH dated 17 June 2008 regarding Interferon treatment. This letter states that I have Hepatitis C genotype 2b;

d. Letter from YDH dated 10 September 2014. This letter states that I have Hepatitis C genotype 1b;

e. Letter from GRO-B Hospital dated 19 September 2012 regarding treatment for Hepatitis C. This letter states that I have Hepatitis C genotype 1b;

f. Letter from YDH dated 6 March 2015 confirming that I do not have hepatic fibrosis;

g. Letter from YDH dated 20 February 2017 confirming that I was being treated for Hepatitis C genotype 1b;

h. Letter from YDH dated 17 March 2017 confirming that my viral load was elevated since starting treatment and that I was to start Ribavirin;

i. Letter from YDH dated 20 April 2017 confirming that my treatment was stopped due to non response;

j. Letter from GRO-B Hospital dated 27 September 2017 regarding the problems with my skin;

k. Letter from YDH dated 29 November 2017 regarding the problems I had with my skin;

l. Letter from YDH dated 27 February 2018 stating that the problems with my skin may be related to my Hepatitis C infection and treatment;

m. Letter from YDH dated 22 June 2018 stating that my skin biopsy showed that the problem with my skin was due to the treatment I was receiving for Hepatitis C;

n. Letter from my GP dated 23 August 2018 confirming some of the problems I had at the time including depression, chronic fatigue, sleeplessness, brain fog, vertigo and exacerbation of Meniere's disease;

o. Letter from YDH dated 9 October 2018 confirming the start of my second treatment for Hepatitis C. The letter also refers to the problems with my skin and that this was causing insomnia;

p. Letter from YDH dated 31 October 2018 confirming a good response to treatment;

q. Letter from YDH dated 13 February 2019 confirming that my viral load for Hepatitis C is now non-detectable.

45. The only difficulties I faced in accessing treatment were in arranging transport to and from the hospitals, as I was unable to drive. My friends had to take me there, which was not ideal. No support was offered to help me get to appointments.

46. As soon as I was informed that I had Hepatitis C, I ceased all sexual relationships and did not attempt to pursue any potential ones. I felt unclean and was worried about passing it on to someone else.

47. I was unable to tell people about my infection and whenever I could I kept it under the heading of 'liver disease'. I cut back on my social life because I was tired all the time and therefore unable to go out.

48. I told my older son about my infection but could not tell my younger son. He is epileptic and suffers from OCD. If I told him that I had been infected I would also be revealing the fact that the incident occurred when he was born, and I know he would blame himself. I do not want that. He is now GRO-B and still does not know.

49. Because of the virus, I felt judged by certain family members and friends.

50. My sister was peculiar around me after finding out. Her contact with us grew more infrequent and whenever we met she acted wary around me.

51. I noticed that if I had a cup of tea, some people would put bleach in it afterwards. This reaction probably stemmed mainly from the lack of knowledge, but it made things uncomfortable for me.

52. I lost three of my friends due to the stigma of the virus. They were paranoid of catching the virus from me and thought that they could pass it on to their families. They believed they could pick it up just from being around me. I have since found new friends who are far more supportive.

53. When I was diagnosed I was working as a therapist. Due to chronic fatigue, I was no longer able to work and had to give this up.

54. Giving up work meant that instead of living on a salary I was living on a pension and Disability Living Allowance (now Personal Independence Payments).

55. I started running a genealogy business from home, doing people's family trees in order to earn a bit of money. I still have a strong interest in genealogy, but since my retirement, I do not do it as often.

56. My sons worry about me a lot, particularly my youngest. He keeps expecting me to pass away and so he doesn't visit me as often. He feels that by distancing himself he will not feel the loss as much. I know his thought process very well. My eldest is better at handling things and he is more laid back and open, although he too is often anxious about me and my health.

Section 6. Treatment/care/support

57. No counselling or psychological support was made available to me in consequence of being infected.

58. I received treatment for my depression through my GP.

59. The Hepatitis C Trust was very good to me and assured me that I could call them anytime I needed.

Section 7. Financial Assistance

60. I have not received any financial assistance for my infections.

61. When I was first diagnosed, I applied to an institution for financial assistance but I cannot recall the name of the institution and I did not retain the paperwork. My application was rejected on the grounds that when I was 20, for a short while I had used intravenous drugs experimentally.

Section 8. Other Issues

62. I am hoping that the Inquiry delivers answers and vindicates people who received infections from contaminated blood products, and have spent their lives struggling as a result.

63. Some form of monetary compensation would be nice; however this is not my primary concern.

64. I believe people were treated very unfairly. After discovering what had happened, I think the medical profession tried to cover the problem up and made no efforts to support people who were affected.

Anonymity

65. I would like to apply for anonymity in order to protect my youngest son and I do not want to give oral evidence.

Statement of Truth

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

Signed GRO-B

Dated 12/9/2019