ANONYMOUS

Witness Name: GRO-B
Statement No: WITN4544001
Exhibits: **WITN4544002 - 07**
Dated: 13 May 2021

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 27 November 2020.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1950 and my address is GRO-B GRO-B I am retired. Prior to that I worked as a psychiatric nurse. I am unmarried. I have one son who was born in 1973 and two grandchildren who are eight and four years old.

2. I intend to speak about my infection with Hepatitis C (HCV), believed to have been acquired from an anti-D injection administered during the termination of a pregnancy in 1971. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact that this has had on my life.

3. I also intend to highlight the fact that my application to the Skipton Fund was declined on the basis that intramuscular immunoglobulins such as anti-D were not considered as possible sources of viral infection during the time in which I received it. Furthermore, I have been informed that my medical records were destroyed. As such I do not possess a physical record of the treatment in which I believe I contracted Hepatitis C. I will go on to discuss this in further detail later on in my statement.

4. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I can confirm that I wish to seek anonymity.

5. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

6. I wish to acknowledge that as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Infected

7. I was born near GRO-B and grew up in GRO-B I went to GRO-B GRO-B to study psychology, but I didn't stay on the course. In around 1970, I started working at an asylum with 2000 patients. I worked there for a while. I then left as I was contemplating whether or not to do my nursing training. I started working in a physics laboratory at what is now GRO-B

8. In 1971, when I was twenty years old, I fell pregnant. I was living in Hertfordshire at the time. I stopped working at GRO-B and did

not return to nursing until 1986 when I completed my training at GRO-B GRO-B

9. For personal reasons I decided to terminate the pregnancy. I was in a relationship but unmarried. The procedure took place at GRO-B GRO-B in Hertfordshire. It was quite unpleasant. I have the doctor's notes with regards to the termination but it doesn't say anything. They never do. Because I was O-RhD negative (-O), I was given an injection of anti-D. This was standard practice at the time for first pregnancies.

10. In GRO-B when living in GRO-B I became pregnant a second time. I gave birth to my son, GRO-B. He was born naturally. There were no complications and I did not receive any blood transfusions. They wanted to give me anti-D. I remember vividly saying that I had received this already. They were assuming that it was my first pregnancy, which it wasn't. I can't quite remember how it was administered but I am sure that it was intramuscular. The dangers of taking anti-D were never discussed with me.

11. In 1992, I received a letter from the National Blood Transfusion Service. I used to donate blood regularly because my blood type, O-negative, is universal.

12. The letter more or less said that blood which I had donated had been found to be infected with what was then known as Non-A, non-B Hepatitis (NANB Hepatitis), now known as Hepatitis C. I was provided with no forewarning from my GP or otherwise prior to this. I was very alarmed to receive this letter because although I was a nurse, I didn't know what it was nor its implications.

13. A meeting with a representative from the National Blood Transfusion Service at the Royal Sussex County Hospital in Brighton was arranged. She was very nice. She asked if I wanted to pursue treatment through my GP or through King's College Hospital in London. I opted to go

through my GP, Dr GRO-B which, in hindsight was a big mistake. He told me to avoid alcohol but other than that, I do not recall being provided with a great deal of information regarding the virus or precautions to take. He was old fashioned in a modern way. He said, 'you'll be alright; you'll probably get ill around sixty. I thought, thanks very much! I liked him though. He was funny.

14. I cannot think of any other time in which I was exposed to Hepatitis C except from the anti-D injection in GRO-B I have travelled but only within Europe. I have never received medical treatment abroad. I do not have tattoos or piercings. Growing up, I was healthy. I used to get bronchitis a lot but apart from that I was fine.

Section 3. Other Infections

15. As far as I am aware, I have not contracted any infections other than Hepatitis C as a result of the contaminated anti-D injection I received in GRO-B Nor do I believe that I have been tested for anything else.

Section 4. Consent

16. I have never knowingly been tested for any infections other than HCV although I presume my blood would have been tested by the National Blood Transfusion Service for various viruses when I donated blood.

Section 5. Impact

17. My diagnosis with and treatment for Hepatitis C has had a significant impact on my personal and professional life.

18. In the late 1980s to early 1990s', when I was working on the drug dependency unit, I did anonymous swab tests for all the punters who would comply, which was the majority. 95% of the clientele were Hep C positive, this was mostly the younger ones as the older users tended to

be very careful. Before I received my diagnosis, I looked after a number of intravenous drug users who had HIV and Hep C. I watched them die because this was before they had viable drugs. Based on my experiences within this sphere, I was very alarmed when I was diagnosed with HCV.

19. Having consulted with my GP following my diagnosis, I was referred to the Hepatology unit at GRO-B for various treatment regimes. In 1996, I began my first course of treatment, Amantadine, an antiviral tablet to be taken orally. This did nothing but keep me awake at night. I think I took this for about three months. During this time, I attended GRO-B every six months or so for blood monitoring.

20. I then decided that I didn't want to go to GRO-B anymore. GRO-B knew too many of the staff. It was embarrassing. I asked my GP to be referred elsewhere. He referred me to Guys and St Thomas'. Both Hospitals were very easy for me to get to.

21. In 1996 at Guy's and St Thomas', I started Interferon which I self-administered through injection. I had these three times a week. It was vile. It was one of the worst things I have ever taken. I became terribly depressed and experienced suicidal thoughts. However, I knew that this was a side effect of the treatment, so I got to grips with it. I started to manage my depression and suicidal thoughts. I wasn't warned of the side effects .

22. The treatment wasn't successful. I started a second course of treatment, this time Interferon and Ribavirin, the latter of which I was given in the form of a tablet once a day. This caused my haemoglobin levels to deplete so that I became anaemic. I experienced breathlessness and fatigue.

23. At the time, I was going to see a wonderful Dutch Hepatitis nurse at Guy's Hospital every 6 months for a check-up. This included blood

tests. Her name was Susanne Johansen. She was absolutely lovely and was always asking me if I would like to be initiated onto a drug trial. However, for a long time there were no trials for my genotype.

24. In a letter dated 25 October 2013, from Susanne Johansen to my medical centre, Dr GRO-B I note that my problems are described as follows:

- Hepatitis C genotype 3.
- Previous failed monotherapy with Interferon in 1995.
- Responder – relapse following 6 months of Peginterferon and Ribavirin – 2004.
- FibroScan 4.5kPa (2009)
- FibroScan 5.1 (2011)
- FibroScan 6.4Pa (2012)
- FibroScan 9.6Pa (2013)

25. Then, one day, just before my birthday on GRO-B 2013, Dr Ivana Carey, the Senior registrar, told me that she would arrange for me to be seen the following day at King's College Hospital for a new drug trial.

26. I went up to King's College in Denmark Hill. There were various trials ongoing, some were given a mix of Sofosbuvir and Interferon. I was given Sofosbuvir on its own for 12 weeks. Others were on treatment for 6 months. The first week I had to attend the Hospital every day from Brighton for monitoring which was a bit of a nightmare. This was reduced to once a week and then once every couple of weeks. The trial was sponsored by a pharmaceutical company so I had my expenses reimbursed.

27. The side effects weren't bad; Nothing I couldn't deal with. I fainted a couple of times and felt a bit sick. I live on my own so I didn't have immediate partner support. On this drug, I didn't experience

depression. The worst thing was the insomnia which caused me to walk around looking half-dead. Apart from that, it was a breeze compared with Interferon. I was just so grateful to be doing it.

28. By April or May 2014, the virus was undetectable. I was called into the office at King's and given the all clear with a cake and some biscuits. I thought, *Hallelujah!* I felt very good. I was so relieved as I was starting to feel quite unwell from all the treatments. I regretted that I hadn't immediately gone to King's after my diagnosis. But never mind, I got there in the end.

29. In the past when I was being seen by Guy's Hospital, I had regular fibro scans. However, I haven't been back to have my liver checked since my treatment ended in 2014. I contacted the Hospital to tell them that I did not wish to be monitored any longer. The journey from GRO-B to the Hospital in Denmark Hill was becoming too laborious. As such, I do not know the current state of my liver.

30. I have arthritis and osteoporosis as a result of which I walk with a stick. Sometimes I can barely walk at all, other times, I don't need the stick. I have had the arthritis since I was in my thirties. No one has ever investigated or informed me that these conditions might be connected with the HCV which remained in my system undetected for several decades. But who knows?

31. For years, I kept my HCV diagnosis to myself. I didn't tell anyone at all. I eventually told my mother and my son, GRO-B but only after a long time. It's not the kind of thing you want to tell your child. I think my son was worried but received the news somewhat like me; he didn't really understand what it was or the implications. I gathered that he did not really want to think about it too much.

32. At the time of my diagnosis, at work I was doing a paper on the transmission of viruses in-vitro. I became very worried that I could have passed it onto my son. He has since been tested which was negative.

However, he wouldn't have known to do this if I hadn't have told him of my infection.

33. Having HCV had a large impact on my social life. On numerous occasions, I would arrange to meet a friend but would feel too unwell and would have to cancel at the last minute. I felt like I was letting everyone down all the time, which to an extent, I was. That was really bad, particularly if I hadn't told people, which I hadn't for a long time. I confided in close friends eventually. On the whole, they reacted very positively.

34. I have witnessed stigma in action through my profession but not directly against myself. I had a patient with HIV and I got to work on the late shift at night. He would be isolated in a side room and on one occasion somebody left his lunch outside. I took it into him. He had some sort of rash. I then took him into the living room for a fag. It shocked me that my colleagues could act like that.

35. I think my profession galvanised me a bit. I needed to learn more about the virus for myself and in relation to my work. I was a bit embarrassed discussing it with colleagues. I discussed my infection with one male colleague. He was absolutely fine. He had a sister-in-law in Northern Ireland who was involved in the anti-D scandal, so he was very understanding. I wished I had told him years before.

36. Prior to my treatment, I was due to see the consultant, Dr GRO-B for an outpatient's appointment at GRO-B There were other people in the waiting area. The receptionist shouted out my name followed by 'Hep C clinic'. This was very embarrassing, I think one should expect to be treated with dignity by the NHS and I didn't consider this treatment to be very respectful of my privacy.

37. At the time of my treatments, I was working nine to five at a community Hospital. My profession has never been easy work to begin with but I got accustomed to dealing with it. I would leave the ward thinking how

no one would believe what I had been through that day! However, when I was on treatment, I would return home struggling to manage day-to-day tasks such as feeding the cat. This wasn't helped by my disrupted sleep patterns.

38. I never disclosed my infection to my employers, nor anyone for many years. It was quite difficult keeping my diagnosis to myself whilst struggling to manage with day-to-day life without any additional support. As a result, I was compelled to take early retirement aged GRO-B because I was so exhausted and to be honest had had enough of a couple of my colleagues who were making comments about my HCV. I remember thinking, I don't need this.

39. I have retained an Occupational health report, dated 30-11-2000, which was compiled by my Occupational Health Doctor, for my early medical retirement. This does not make good reading. At para F. The handwritten entry states: '*Prognosis for the Hep C uncertain when I saw her 5.10.00 she looked terminally ill so I am surprised her LFT's are normal. I suspect the fatigue is largely responsible for appearance. GP is of the opinion that she is likely to remain unwell*'

40. On page 9 of the report. Under the heading – '*Terminal Illness. In your opinion, is the member's life expectancy less than one year?*' The word '*possibly*' has been recorded. Unfortunately I cannot remember the name of the Doctor who compiled this handwritten report. I produce a copy of this as my exhibit **WITN4544007.**

41. As a psychiatric nurse, we can retire at 55. I took retirement five years early which makes me really sad because I didn't get a very good pension. I receive £120/130 from the state pension and about the same from my NHS pension. Nevertheless, I am grateful that I have something.

42. For a while I was on state benefits, I believe this was referred to as 'invalidity' benefits. At one point, this was stopped. So, I had to appeal

the decision. I was living on £30 a week which was awful. I lived off almost nothing. No one could believe how I managed. My mortgage is now paid off but my place is falling apart. Since my mother died, I've got a bit of money to do small repairs.

43. I never told the dentists. They always wear masks anyway. I did tell someone at work. As I said earlier, there were a few people there who looked down on me. This contributed to my early retirement.

44. Sometime after 1980 when I moved to GRO-B I became a blood donor. I donated blood until I received my diagnosis in 1992. It was quite upsetting because I knew that my blood was useful and the donation service were always asking for it. I always thought that this was a reasonable gesture. Theoretically, I could now donate blood but I still have antibodies for HCV so this wouldn't be accepted.

45. I did ask the Blood Transfusion Service if they could trace whom my blood had been given to. I was very conscious about that, I thought I was doing a good thing, which now in hindsight could have been bad.

Section 6. Treatment/Care/Support

46. Prior to treatment, I was given a liver biopsy at the Royal Sussex County Hospital. However, the doctor's initial approach to the procedure concerned me. I think he was only a Registrar. He did not conduct any blood tests prior to the biopsy nor did he check my INR which indicates the patient's clotting rate. This is routine practice for a liver biopsy.

47. I was terrified as the procedure is intrusive and involves a great big needle. As such, I requested for someone more senior. I have since had numerous liver biopsies. They are very unpleasant. You then have to keep still for six hours. The outcome has always been chronic Hepatitis C.

48. I know that I have had persistent infection but as far as I am aware I do not have cirrhosis or any scarring. I knew somebody who had to face the possibility of a liver transplant. I was never confronted with that sort of prognosis.

49. I was never offered any counselling or psychological support when I was diagnosed with Hepatitis C. I was shocked when I opened the letter. I was on my own and kept my diagnosis to myself for many years.

50. I am a trained counsellor aside from my nursing qualifications. However, I am not sure that counselling would have been helpful to me at that point.

Section 7. Financial Assistance

51. On 9 April 2014 I applied to Skipton. This was received on 9 June 2014. I think I had heard about the fund and then discussed it with the senior registrar, Dr Carey at Guy's and St Thomas'. She was a lovely doctor and helped me to fill out the forms.

52. I produce a copy of my original Skipton application as **WITN4544002.** Dr Carey supported that I received anti-D antibodies in relation to pregnancy as an O RhD negative (-O) patient and that I was provided this in June 1971 at GRO-B following the termination of a pregnancy. She expressed her view that I acquired HCV through the application of anti-D globulin and that in the presence of 'no other risk factors for HCV and other blood borne viral infections', there could be no other source of infection.

53. It would appear that Dr Carey included the following documentation in support of my application:

A letter from GRO-B to Dr GRO-B on 2 July 1971 which confirms that my pregnancy was terminated. I exhibit this document as **WITN4544003**;

A letter from GRO-B the Consultant Gynaecologist at GRO-B GRO-B on 7 December 1971 which confirms my blood group as O-RhD negative (-O). I exhibit this as **WITN4544004.**

54. On 20 June 2014, my application was declined 'due to the lack of supporting confirmation that [I] was infected with hepatitis C through treatment with NHS blood or blood products prior to September 1991'. I exhibit this document as **WITN4544005.**

55. In Skipton's refusal letter, they added that they were 'informed by The National Blood Service (NBS) that anti-D immunoglobulin produced by Bio Products Laboratory (BPL) in England and Wales and the Scottish National Blood Transfusion Service (NBTS) in Scotland was safe and therefore not a possible route of hepatitis C infection'. They enclosed a copy of a literature review (referenced below) to support their position that viral infections could not be transmitted by intramuscular immunoglobulins.

56. The literature review is exhibited at **WITN4544006.** In the concluding paragraph, the author notes: 'There have been reports of hepatitis C developing in pregnant women given anti-D intravenously (East Germany and Republic of Ireland). In these two instances not only was the anti-D given intravenously, but the manufacturing process did not include the full ethanol fractionation step which has been shown to be important in reducing the risk of HCV (NANBHV). The main purification step used was chromatographic. The roots of that process go back to 1973 when Hoppe *et al* published an ion-exchange chromatographic step instead using ethanol fractionation. This step was very suitable for manufacturing anti-D on a small scale. There have never been any outbreaks of HCV (or NANBHV) following the use of intramuscular anti-

D since the late 1960s: an outcome which is as expected from the vast experience with IMIG and IVIG.'

57. I never appealed this decision. I was too exhausted. I had been cleared at this point and just wanted to draw a line in the sand. I was quite fed-up. I couldn't conceive of any other route of transmission. I have never had a blood transfusion or even needle-stick injuries. I have had near misses but these were after my diagnosis. If I had had a needle-stick injury, somebody would have been there as in my line of work we didn't work alone; it would have been disclosed and recorded as a work place injury.

58. I am concerned that I have no more of a case now than I did then. One of my GPs was very kind. He sought to get hold of my medical records. However, he was told that it was routine policy for these to be destroyed after 8 years. I find this unusual as every hospital I have worked in have retained records for at least fifty years. When I first started working at the asylum in 1970, there were records going back 100 years. In Brighton General Hospital, records went back at least 50 years and sometimes longer.

59. I am now faced with a situation in which even if the EIBSS recognises that HCV can be transmitted by intramuscular anti-D, I do not have my medical records to confirm that I received this as they have allegedly been destroyed. However, I know that in 1971 I was given Anti D, because if they hadn't, I wouldn't have refused it a couple of years later. Moreover, with my blood group, anyone would know that it was common practice at the time to administer this for first pregnancies.

60. I am aware that in Northern Ireland, a class of women mass sued the government for contracting HCV through anti-D globulin so they must have had the same jab as me.

Section 8. Other Issues

61. I would like to know how this has been allowed to happen and why the government at the time did not inform anybody about the risks associated with blood, blood products and immunoglobulins such as anti-D.

62. They must have known as they were allegedly importing blood from dubious sources.

Statement of Truth

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

Signed GRO-B

Dated 13-05-2021

Table of Exhibits

Exhibit number	Year	Description
WITN4544002	09/04/2021	Original application to the Skipton Fund supported by Dr Ivana Carey
WITN4544003	02/07/1971	Letter from GRO-B GRO-B to Dr GRO-B re;

		termination of pregnancy, enclosed as part of Skipton application
WITN4544004	7/12/1971	Letter from GRO-B GRO-B to Dr GRO-B re; (-O) blood group, enclosed as part of Skipton application
WITN4544005	20/06/2014	Letter from Skipton to Mrs GRO-B re Skipton Fund refusal
WITN4544006	Undated	Literature Review, 'Lack of Transmission of Viral Infections by Intramuscular Immunoglobulins' enclosed as part of Skipton's refusal.
WITN4544007	30-11-2000	Occupational Health Report