Witness Name: GRO-B
Statement No.: WITN1908001
Exhibits: WITN1908002-WITN1908008
Dated: 10 June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B at birth) and my date of birth is GRO-B GRO-B 1968. I am currently single and live with my cat Scarface. I have one sister who lives close to me and have a few good friends. Most of my family (on my Dad's side) live in Scotland. My address is known to the Inquiry.

Section 2. How Infected

2. In 1968 as a newborn baby, I received three times exchange transfusions which took place at 36 hours, 63 hours and 85 hours after birth in Edinburgh at the GRO-B Hospital. Tests on my blood showed that I was affected by Rhesus isoimmunisation.

3. Sadly, my Mum has passed away but no discussions took place reference any blood borne viruses. (I am glad Mum never knew about this).

4. I was infected with Hepatitis C as a result of blood transfusions at birth.

5. It was 7 March 1995 when I received the news that I had Hepatitis C. I remember it well. I had donated blood a few weeks earlier at my place of work. Now, I was receiving a letter in the post from the blood transfusion

service informing me that I had a potentially deadly disease! They were also going to write to my Doctor. **(WITN1908002).** At work, when every other blood donor got a reminder to give blood again, my desk was noticeably absent! After this happened, when other temporary workers were offered permanent positions up in Edinburgh (as Customer Accounts were moving from GRO-B to Edinburgh), I was only offered a temporary position. However, I later found full-time permanent employment elsewhere.

6. I was 26 years old at the time and believe me, it was like being hit by a truck, (I understand people are not sent letters anymore). At that time, I wasn't sure if I only had 6 months left to live!

7. Anyway, I made an appointment to see my GP. To be honest, if I had been aware of Dignatas at that time, I would have been on the first flight. I was so traumatised. My GP Dr GRO-B (GRO-B Health Centre) was very understanding and appeared to be sympathetic. I would also like to add, that even after he retired many years later, he continued to help me by answering my calls on my dark days.

8. Even now, many years after my diagnosis, I still struggle to go back to that time in my life. Anyway, appointments were made for me at the liver clinic at Freeman Hospital and my diagnosis was confirmed. **(WITN1908003).** I had been given a sick note for 2 weeks with the reason debility (if I remember correctly) and I think that means that my GP is not giving the reason. I was advised that I was given the virus in a blood transfusion which I had received in Edinburgh at birth in 1968.

9. I could not see a future, I had just completed a full-time college course in Business and Finance, NVQ level 3 in Administration with Secretarial skills and was temping and trying to get some experience. Just at the start of a secretarial career and now I was unable to lift a cup of coffee without my hands shaking. I couldn't even write a suicide note. I know this sounds like gloom and doom but that was where my head was at the time. I very nearly had a nervous breakdown.

10. I have never been able to accept my diagnosis; I struggle to even talk to anyone about it without breaking down. The hospital visits were a complete nightmare for me and I suffered panic attacks and nearly fainted on one occasion. The Professor who I saw in the beginning was very, shall we say, relaxed about the whole situation but I was dying inside. I felt so petrified and I couldn't sit in the waiting room because I was seeing yellow people with their hair falling out, I was absolutely mortified. No one seemed to understand what was wrong with me! My head was in total denial as to what was happening to me. It was like being part of a horror movie.

11. It is all a bit of a blur to be honest but I remember being given a red A4 booklet about Hep C, I think the Freeman Hospital provided this to me. It had things like treatment options and symptoms in. I remember seeing something about a 10% success rate after treatment.

12. I do not feel the information provided in the booklet was adequate. At the time, I wasn't sure if I even had 6 months left to live!

13. I received the booklet as soon as the Freeman confirmed my diagnosis.

14. In 1995, I donated blood and was informed I had Hepatitis C in a letter! The way it was communicated almost killed me, not to mention that someone else could have opened that letter as I was living in shared accommodation at the time. It is the hardest thing in my life I have ever had to deal with and unfortunately, I will never get over it.

15. At the time, I was advised that Hep C was not sexually transmitted. I was told "If it was hepatitis B I would be telling you something different". I was not given any other information about the risks of infecting people.

Section 3. Other Infections

16. I have previously been vaccinated against Hep A and Hep B but I am a bit confused as, in a letter from Freeman Hospital to my GP, dated 07/10/2010 it says "Her liver screen was negative for other liver diseases. She has had

previous hep B and Hep A so does not require vaccination?" **(WITN1908004).** I think that means that Hep A and Hep B showed positive because I had been vaccinated?

Section 4. Consent

17. I participated in a drug trial, so I guess it was for the purposes of research. (See below for details of my treatment).

Section 5. Impact

18. Unless you have been directly affected by this tragedy, it is impossible for anyone to understand the mental impact. It changes everything. You feel like a nothing, a nobody no matter what profession or position you hold. You tolerate unacceptable behaviour from medical professionals as you know that you are now classed as a contaminated being and no one else will probably take you on. Your life as you knew it is no more, a black cloud will follow you around for the rest of your life. You can blank it out and carry on as best you can but eventually it will eat you up.

19. You spend your life in pain (mentally and physically). Every joint and muscle hurts. You learn to live with it and it becomes normal to you. You sleep a lot and have little or no energy. Your get up and go has got up and gone.

20. Other medical conditions that I suffer from are;
    - Severe fatigue
    - Facial hair
    - Indigestion
    - Hiatas Hernia
    - Depression and Anxiety
    - Osteoarthritis
    - Back pain (lumbar disc prolapse with radiculopathy)
    - High blood pressure (seems to have returned to normal now)
    - Bacterial infections (re-current boils)

- Thyroid (recently prescribed Levothyroxine sodium 50mcg tabs), repeat blood tests due in January 2019
- Geographical tongue
- Skin infections (recently prescribed 15g Fusidic acid)
- Severe streaking of the oesophagus
- Fibroids
- Hair loss
- Swollen abdomen (occasional sharp pains)
- Eczema
- Very dry skin
- Degenerative changes affecting the great toe metatarsophalangeal joint
- Possible poor circulation as I am always cold
- Possible IBS (suggested in my notes from the Freeman Hospital)

21. I can't confirm if any of these are as a result of my Hep C or the treatment that I received accept the depression and anxiety.

22. I also have days where I can't describe what is wrong with me, I just ache all over and appear to be shivering on the inside.

23. At the end of 2012, I decided to have treatment. I was originally prescribed interferon and ribavirin but due to high blood pressure they had to take the interferon off me and arrange alternative treatment. **(WITN1908005).**

24. Subsequently, I took part in a trial which included ribavirin and faldaprevir for chronic genotype 1 hepatitis C, which apparently is the worst one to treat. The details of the trial are as follows **(WITN1908006).** :

    Study Title; A phase III randomised, partially double-blind and placebo-controlled study of B1207127 in combination with Faldaprevir and ribavirin for chronic genotype 1 hepatitis C infection in an extended population of treatment naive patients that includes those ineligible to receive peginterferon. Study Number; 1241.36. Short study title; B1207127 in patients with HCV.

25. I have definitely gone downhill since then, tiredness comes and you have to sleep, I have constant back pain since March 2016, scans show that L4 and L5 are out. I also have to manage my depression, abdominal pain and swelling (I look pregnant) and severe joint pain. My blood results thankfully showed I had cleared the virus after treatment. **(WITN1908007).** I was also forced to go for a work assessment in order to receive my benefits whilst having treatment in which they advised I was fit to work! I did successfully appeal this decision in 2013 but not without stress.

26. In the letter sent from my Consultant to my GP, it states "Follow up has finished earlier than originally anticipated as the pharmaceutical company are not taking the development of this drug any further". **(WITN1908007).**

27. I did not experience any difficulties in accessing treatment, although it was many years after my diagnosis.

28. I do not know if there are other treatments that should have been made available to me but I think this needs to be investigated.

29. Not sure why but I actually feel worse now than I did prior to having treatment. My joint pain is more severe and my fatigue is debilitating. The whites of my eyes went yellow and the skin on my face and neck started peeling during treatment.

30. Regarding my osteoarthritis in my knees, I was advised years ago that I was too young to have knee replacements, (this may have been the case?).

31. In March 2016 when I rang my then Doctors, Dr GRO-B (Dr GRO-B had retired by then) at GRO-B Health Centre, who I had been registered with since approximately 1992, to make an appointment for my back, the receptionist advised me I was no longer with their Practice and that they had sent my medical records to some central location due to my change of address and I no longer came under their catchment area. **(WITN1908008).** During that phone call I was also advised that the Practice Manager was not at work and the

Supervisor refused to speak to me! I know the Receptionist felt bad for me; she was in a difficult situation.

32. This caused me a lot of unnecessary extra trauma, I had to register nearer to where I live, which greatly increases the possibility of a breach of confidentiality. I was in absolute agony with my back, so I had no choice. I even wrote a letter and practically begged to stay with my original practice and advised I would agree not to have home visits but to no avail. I hadn't even been informed!

33. Back in 2010, I was diagnosed with a 5.9cm cyst in pelvis which appears to relate to the right ovary. I was later advised this disappeared on its own. Note, I have recently received a letter for another scan for 24 January 2019 and I have had a few other scans in between.

34. I moved to my current address in August 2010 and Dr GRO-B sent a letter to my previous address (where post had knowingly gone missing as there was a shared entrance and the upstairs neighbours were the reason I moved) discussing my Hep C and possible compensation options, this was totally unnecessary. If I remember rightly, I had a re-direction on my post, so I actually received this letter at my current address. There was also a letter sent out from them to number GRO-B instead of GRO-B which is my current and correct address but unsure of its contents. On my notes, there also appears to be a made-up address at one point.

35. Sometime after receiving my devastating news, my hair started falling out. My GP referred me to a Dermatologist at GRO-B Hospital, also known as (GRO-B). I was nervous about attending as my GP has to inform medical staff about my condition. When I arrived, the female Consultant had a group of trainee students with her which I had not consented to. The first words out of her mouth were "So you have hepatitis". Needless to say, I was mortified. I guess, that was one way of getting rid of me. I drove home in tears and that experience made the terror and fear that I already felt so much worse.

36. It may not be true but I do feel as though I won't be offered the best treatment for anything as I am classed as damaged goods and not worth investing in. I also smoke which helps me with stress management but I guess that makes a good excuse also.

37. My Dentist is fantastic and I have never experienced any problems with their practice.

38. My family life has been affected but I have not discussed my illness with them. Sometimes I am too tired to answer my phone or I have to cancel arrangements due to tiredness. My social life has also been affected due to fatigue. I often have to cancel gym classes, Spanish evening classes and socialising due to feeling too tired. If I have something planned, I have to sleep before in order to attend. As far as a private life is concerned, I don't have one. I never had children as I would never in a million years risk a child going through what I have experienced. I have never allowed anyone to truly love me, I have pushed them away.

39. My family is unaware of my condition. I have not told family or friends about my illness as I do not want to burden them or for them to worry or treat me differently or possibly avoid me altogether.

40. I did not do well at school but have since and for many years studied and got reasonable results. I am currently studying Spanish at a night class and not doing as well as I once would have done. I do enjoy learning and always have since leaving school but whereby before I worked two jobs and studied, I now struggle just to attend an evening class.

41. Over the years, I managed to put this disease to the back of my mind and actually did quite well at work and managed to buy my council flat through the right to buy scheme. This was good for me as my mortgage actually cost less than my rent and because of the positive equity in the property, getting a mortgage was no problem as I did not require life insurance. Not, that they were aware of my diagnosis, I don't think.

42. In order to continue working for as long as possible, I retrained as a Beauty Specialist in 2012 and was self-employed at home from approximately September 2013 but now even that is not practical as I don't know what I am going to be like from one day to the next so cant book appointments in advance. Some days I just can't get out of bed. My mind wants to but my body doesn't. I also took in lodgers in the past to boost my income as I am in a good location for GRO-B

43. I have suffered financial loss as a result of my condition. I had to give up my career due to my illness. This was a job I loved, and provided me with many amazing life experiences that I otherwise would never have got the chance to do and I will always be grateful for that.

44. I also fostered children for a short time in 2014 - 2015 but I resigned from that position. The Agency lost my file with all my personal information in and I mean my whole life. I was expected to deal with the most challenging behaviour (including serious mental health issues) even though I was a new and inexperienced carer. I was expected to drop off and pick up a child three times a day through the GRO-B and was bombarded with phone calls. I feel as though I was set up to fail. It was a shame as back then I could have provided a vulnerable child with a lovely home. However, this is why I know I did the right thing in the past by keeping my condition quiet, at least I had a chance.

45. My sister is my only relative who lives close to me and she is unaware of my condition. My parents are deceased and I have no children and no partner. I have family in Scotland who are also unaware of my condition. One of my Uncles visits me occasionally. I do live quite a lonely life but I do also have a handful of good friends. I do miss the companionship of male company but have learned to be content on my own.

Section 6. Treatment and Support

46. The treatment and care I received was good and my specialist nurse was genuinely caring and was always there for me on time for my appointments as

she knew I suffered severe anxiety just getting through the hospital doors. However, when she went on holiday. I saw a younger nurse who clearly did not want to see me and was late for my appointment. My usual trolley was all set up ready with all the equipment required but she sent another nurse to get another needle to take my blood? When I mentioned this at my next appointment to my Consultant, I was advised that she no longer works there! That incident still concerns me to this day.

47. From 2005 - 2013 I also had to deal with a severe case of anti-social behaviour, which felt like torture, (floods to my flat and post going missing from the shared entrance), noise, nails in my car tyres, etc, which left me so desperate I borrowed £90.000 and bought another house to escape. I sometimes even slept in my car rather than going home. Later, I eventually sold my flat under market value because of the damage. This was also a very worrying time for me which spanned over eight years. I wasn't really in a position to start again given my deteriating health but the gamble did pay off thankfully.

48. GRO-B Council were the Freeholders of my flat but unfortunately did not enforce the covenants of the Leasehold, much to my detriment. I am unsure if they were aware of my condition. They also arranged for necessary building works to commence at the same time as I was having treatment despite me advising them of the dates that I would be having treatment for a serious illness! This meant that I had to go back to the flat twice a day to let builders in and then lock up at night. I remember having to wear a scarf as the skin on my neck was peeling off, my eyes were yellow, not to mention how ill I felt some of the time.

49. At my new GP Practice, GRO-B in GRO-B, I was allocated a GP that worked one day a week. Anyway, due to all my symptoms I went back to my liver hospital, the Freeman and they wrote to my current, new Doctors transferring me back to their care but to do follow up tests as I had bloating, etc possible IBS.

50. At every appointment, I was being allocated a different GP, I saw Dr GRO-B, Dr GRO-B and a couple of others and in my notes, I noticed that different GP's stated that I said my transfusion's took place in the 80's and 90's! When I last saw Dr GRO-B who is now my allocated GP, I advised her of this error and she did update the record with the correct information.

51. At one of my appointments their information was wrong and they didn't know what blood tests they were meant to do and also, they subsequently lost my stool sample! My new GP works 3 days a week but at my last visit I was advised I only had 10 mins and she hadn't read my notes! I must add, that I now, very recently appear to have a GP that works full-time. The other GP's were lovely also and one even apologised to me for what has happened.

52. I would also like to mention in GRO-B s defence, that at the time, there was a lot of changes going on as a couple of Practices were merging and with staff changes, etc, mistakes were bound to happen.

53. Not long after my diagnosis, I was offered counselling but I honestly was too embarrassed to go. To this day, I still find it difficult to talk about.

54. My current GP Dr GRO-B of GRO-B did give me a telephone number for talking therapies but unfortunately, when I rang, I felt as though I had interrupted the call handler's conversation and would not have felt comfortable discussing my issues with her. I decided to leave it. I can't discuss it without breaking down so I feel counselling will just upset me more.

Section 7. Financial Assistance

55. My then GP Dr GRO-B advised me about The Skipton Trust in 2006.

56. I received £20.000 from The Skipton Trust in 2006 but no ongoing payments as my earnings were too high as far as I can remember.

57. I believe that I received the following payments from the Skipton Trust but not 100% sure.

a. 2012; £1500.00
b. 2013; £6257.62
c. 2014; £1400.00
d. 2015; £5816.70
e. 2016; £5013.31 + £30,000 (a one-off payment made on 22 Dec 2016)
f. 2017; 335.34

58. I believe I received the following payments from SIBSS:
a. 2017; £5930.74
b. 2018; £11,298.11

59. My GP completed the relevant paperwork from The Skipton Trust then the application was sent off.

60. I did not have any difficulties or obstacles when applying for this payment.

61. To my recollection there were no preconditions imposed on me whilst making this application. There was a little uncertainty regarding on-going payments.

62. Some of my payments have been on the low side because I am single although I am grateful for any help. However, the payments that I receive now (Dec 18) are more realistic.

63. Over the years, I worked very hard and I am lucky enough to own my house outright as I wanted to put myself in the best possible position to cope with life, (if I was still alive)! I was kind of given notice of death. I had no desire to be homeless and dying. I didn't want to be a burden on the state as I was a very private and proud individual.

64. However, due to worsening symptoms I have recently signed on, my first payment being 22 June 2018. I first rang on 12 April 2018 and was on the phone for about an hour if I remember correctly. A meeting was set up for me. When I arrived, I was advised that I couldn't claim that particular benefit and was advised to go home and ring a different telephone number which I did.

Bearing in mind, how difficult it is for me to even discuss this situation, I didn't ring again until May. Anyway, I have now signed on for Universal Credit and have to say that the 2 people who interviewed me showed great respect and understanding for which I am very grateful. I currently receive £317.82 pcm Universal Credit, the first payment being on 22 June 2018 and my Council Tax has been discounted for some time. I also receive £641.56 pcm from the Scottish Scheme, (see below for updated details). I was previously registered with The Caxton Foundation and my details were transferred to the Scottish Scheme.

65. As of 15 December 2018, my new monthly payment from the Scottish Scheme is £1575.00 pcm. I received £3375.32 on 14 December 2018 as this payment was backdated to September 2018.

66. I had to attend a health assessment on 13 December at GRO-B and anyway, I never received a Universal Credit payment in December. However, on 8 Jan 2019, I received a backdated payment for £2,224.74p from DWP. I got an apology from them and as far as I am aware, they had spoken to SIBSS regarding this matter. On 16 Jan, there was a letter in my journal advising that I do not have limited capability for work and can do some type of work. This means you might be expected to look for work, depending on what you have agreed with your work coach. I will keep you informed of any changes.

67. Over all these years, I have had a big black cloud hanging over me. I have been unable to maximise my potential in my career; I have also lived a very lonely life. At one time, I even cut myself off from my friends and family because I didn't want them to miss me, so I tried to get them used to not seeing me. I later decided this was not the right thing to do, we all need people in our lives.

68. I don't want to have to beg for money, I want to live my life with dignity and respect and to be comfortable. At the end of the day, I would more than likely still be working and earning today if this had not happened to me.

Section 8. Other Issues

69. I do worry about what the future holds. In some ways, I wish I had not donated blood that day, I think it would have been better not to have known. I have never been involved in any earlier litigation. I cancelled a pension when I was an employee with the GRO-B, where I worked for eight years. I obviously did not want to pay into a pension when I thought I was going to die and probably will prior to ever getting to pension age.

70. I have received a copy of my medical records including details of my blood transfusions.

71. I hope the inquiry will expose those who decided to play Russian Roulette with our lives and for a long time, left us to die with no financial or medical/psychological support for the physical and mental trauma not to mention the stigma that we have all experienced in different ways.

72. I want the Inquiry to provide accountability and financial stability for the remainder of our lives.

73. I was advised my treatment for hep c had a 70% success rate in America but I do question why the trial was stopped. I was not given any information regarding this.

74. There has been a partial loss of some of my medical records and also an incorrect date that I had corrective surgery for the second time on my lip. There are also a few other minor discrepancies.

75. I have received my medical records but not sure that they are completely accurate and complete.

76. I always felt like a second-class citizen due to my condition. Also, as previously mentioned, the Doctor who brought the students in to look at me which caused me considerable embarrassment and distress.

77. GRO-B Health Centre just removed me without my knowledge and despite me agreeing to not having home visits as I had moved out of the catchment area, they had absolutely no regard for my feelings. This was very upsetting for me and caused me severe stress. The Supervisor even refused to speak to me on the telephone, absolutely disgusting.

78. My current Health Centre in GRO-B lost my stool sample, the GP wouldn't take my blood and so I had to make another appointment with the nurse. There were big changes at that practice going on at the time but I still feel disappointed. I sometimes wish I didn't have to see any NHS employees ever again.

79. My work coach has been really polite and kind to me and appears to actually understand my situation. However, as my Health Assessment advised that I could do some kind of work, I still feel pressurised to seek employment despite me trying to explain that I suffer from fatigue amongst lots of other things as previously mentioned. It would be difficult for me to do set hours as I do not know what I am going to be like from one day to the next. I am trying to keep myself fit and do visit a gym but do have to cancel classes on many occasions. If I had to work, I may never get to the gym and I am sure this would cause my mobility to suffer even more.

80. The DWP overpaid me in January 2019, and I currently get £270.15 pcm, they are taking £47.67 pcm of a total of £317.82 which is what I was originally being paid. They just deducted the £47.67 without notifying me in writing or over the phone. I do not receive housing benefit as I did not want to be a burden and got plenty of notice of death and paid of my mortgage. The overpayment was made on 08/01/2019 for £1906.92, I questioned this at the time and was advised that they had spoke to SIBSS and this payment was correct. What can I say?

81. The staff at the Charitable Trusts have mostly been helpful to me and have helped me a few times with one off payments for different things. My monthly payments were quite low though as I had no dependants and was single.

Statement of Truth

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

Signature GRO-B

Dated 10 June 2019……