Witness Name: Mrs GRO-B
Statement No.: WITN1925001
Exhibits: 0
Dated: 13 February 2019

WITNESS STATEMENT OF MRS GRO-B
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry.

2. I live on my own. I have three daughters who are 34, 33 and 25. I also have two grandchildren; a girl who is 14 and a boy who is 11. I have always lived on my own except for when I was rearing my children, when they lived with me. I am not well enough to work and I never have been.

Section 2: How Infected

3. I was infected on GRO-B 1984, when I was only 17 years old. I gave birth to my first daughter at Jessops Hospital for Women in Sheffield. Following the birth I began to haemorrhage, I told the nursing staff I was in serious pain, but they did not believe me. It was not until I stood up that they realised I was in trouble as I had lost a lot of blood. They panicked. I was rushed to theatre and I do not remember anything else until I woke up. When that happened there

were two drips attached to me; one was blood and the other contained clear liquid. My mother-in-law told me that I had a blood transfusion and explained she had to sign something so I could be operated on; my own mother was at work and it was miles away. I remember that after the operation I was extremely ill. I was in hospital for seven days, I was so ill I could not look after my baby. I had to have nurses with me all the time to look after my daughter and to help me with everything.

4. I was not infected as a result of my relationship with another person.

5. I was not given any information beforehand about the possibility of a risk of being exposed to infection. My mother-in-law did not tell me there was a risk attached to me receiving the blood transfusion; she just said that I had a blood transfusion.

6. I was infected with hepatitis C.

7. In around 1999, I went to a sexual health clinic to make sure that everything was alright with me. I was suffering some mild symptoms that turned out to be related to the soap I was using. The staff at the clinic mentioned that they were testing for hepatitis C that day and asked if I wanted a test. I said yes ok. I cannot remember whether I receive a follow up appointment but I know that I had to go back in to see them for the results. A young gentleman and a young woman took me aside and told me that I had hepatitis C. They gave me a leaflet and sent me home.

8. I was given a leaflet by the Sexual Health Clinic that contained information that I recall was very vague, I remember there was something on there about not sharing toothbrushes, razors and needles. I do not think that it was informative as I had to go and look up what it meant but I know it scared me because I thought about my daughters and us sharing our razors and toothbrushes. The information I was finding out made sense to how I was at time, I was suffering from the symptoms that were mentioned in the leaflet. I was always so very

tired, all of the time. I had a lot of pain in my joints for a long time. So when I looked it up, it all made sense.

9. I was not given adequate information to help me understand and manage the infection by the people who told me. The next thing I recall was arriving at the Hepatitis C Clinic in Sheffield Hospital extremely stressed and eager to find out more about what was happening to me. I do not remember how I managed to get there; whether I was referred by the Sexual Health Clinic or by my GP, I do not know. The Hepatitis C Clinic was not concerned about where I had got the infection from, but I was. It seemed to me that they were more concerned about pushing their treatments on me. I could not believe this because I was struggling to understand what the infection was and I needed to get to grips with understanding that first. I was more concerned about my children and the possible risk to them. I asked that my daughters be tested and we made arrangements for that to happen, so I had to explain to all three of them what it was all about. This was extremely difficult. My eldest daughter went completely off the rails. The Hepatitis C Clinic gave me a booklet but I still felt like I did not understand enough about it. The one thing that stands out to me now about the booklet is that it contained a lot of information about intravenous drug use. I was not ever given adequate information to help me understand and manage the infection; I had to self-educate myself and by luck I stumbled across the Hepatitis C Trust soon after I was told and the staff there were very supportive; they explained everything to me and helped to understand and manage. They became a counselling service to me.

10. Yes, I should have had proper information provided to me earlier because my research really scared me and initially I had no one to check this with. When I was being told, I did not realise that it was as serious as it was because they told me in a very matter of fact, you do not need to worry way. I think I should have known about there being a risk of receiving a blood transfusion just after it was given to me.

11. What I was told and how I was told was not enough. I do not know why the

Sexual Health Clinic gave me so little information; I ask myself now whether they were trying to protect me or just not bothered at all about what was happening. What I was given was quite brief and I managed to get the majority of information through my own research.

12. I was given one leaflet by the Sexual Health Clinic which contained some information about the risk of others being infected including through sharing toothbrushes and razors and needles. It was wholly inadequate and I felt the need to do my own research to answer the questions I felt I needed to be answered.

Section 3: Other infections

13. No, I have been infected with hepatitis C only.

Section 4: Consent

14. Yes I believe I have been treated and tested without my knowledge, without my consent, without being given adequate information and for the purposes of research. I think that the authorities knew about the hepatitis C in the blood transfusion I received at Jessops Women's Hospital because I believe that a 17 year old girl who is pregnant with a baby is a good person to test on. I think that they were testing how I could cope with contaminated blood in my body and to see whether my child might become infected through breastfeeding and being in contact with me. I have requested my medical records. The GP records I have received tell me that only some of my medical records have gone missing; very oddly there is a period of time from August 1983 where there is only one piece of information saying that I am pregnant that then there is nothing. There is nothing more about me being pregnant, nothing about me giving birth, nothing about the operation, nothing about any of it. Nothing about my eldest baby. This gap goes on until September 1985, which is one month after I had my second child. I have also contacted Jessops Hospital to get my records, there are records missing from their records too during the exact same

period of time; August 1983 to September 1985, they have said this is because they experienced a flood.

15. In addition to this I have had hepatitis C treatment pushed down my throat. I did not consent to the side effects that it eventually brought and I would never have had it had I known what it was going to do. It has completely ruined my life. Before I started it, I was functioning with the hepatitis C, I had symptoms but the treatment brought something entirely different to my life and it has been unsuccessful.

Section 5: Impact

16. The impact of the hepatitis C has been immense.

17. Physical and mental effects: I started to get symptoms when I was around 22 or 23 years of age, at that point I would have been carrying the virus for five or six years. I remember I was getting a lot of pain in my back and I was having a lot of physiotherapy and acupuncture. I was not sleeping well, and I started being unable to concentrate or make decisions. I was what I would describe as being "all over the place". I was always sick with the flu including coughs, colds, ear infections, sinus infections. I had lots of testing done and everything was put down to stress so I just got on with it. My immune system is completely shot; my white blood cells are down to 0.05. I suffer from chronic fatigue which also makes me feel nauseous; for me this means that I have to cancel half of my life because I need to sleep. I sleep 12 hours per day. I cannot control my body temperature especially from being cold. I have low blood pressure and I get very cold; it is like my body shuts down. My hands, feet, toes and face are in a lot of pain, my while body aches, sometimes the pain is so bad it is hard to walk or use my hands properly. I cannot open things, tie laces, grab zips. I also suffer from migraines on a monthly basis. I have dizzy spells and I have fallen over in the past. I have severe allergies including an incessant itch which drives me insane. I also suffer from incontinence. I forget things all of the time; my memory has been badly affected, it is difficult to take information in. At

times I feel like I am a lot older than I am, like an 80 year old woman. The mental side effects include stress, and an inability to cope with everything. I try to not think about this as it is too much. I am a lot better than what I used to be but I have to cancel a lot of things in my life to protect myself. I lead a very controlled life. For example, I cannot call gas or electric companies as it gets too much for me. I have to have someone else do this for me. I worry constantly that the cancer is going to come into my liver or somewhere else in my body now.

18. I suffer with Myalgic Encephalomyelitis. A year and a half ago I was diagnosed with throat cancer and I believe that this was partly due to the drugs I took for the hepatitis C and partly due to the stress after the treatment. I had a 16 hour operation; my face was slit open from ear to ear. The cancer was in my throat and my mouth and in the lymph nodes. This is why I had so many problems with my sinuses and ear infection. They removed the nerve from my tongue to my brain so only half of my tongue works. I lost the ability to swallow and the ability to talk. I had to learn how to eat and swallow again. I still cannot eat certain foods and I end up choking a lot of the time. They removed a lot of lymph nodes the left side of my body. They removed the artery from my left arm and put it into my mouth. Due to the operation, my top five vertebrae in my neck are twisted and my hip, knee and feet have moved out of alignment. I see a chiropractor for this. I have numbness in my chin, throat, and on top of my left chest, left arm and across the left hand side of my shoulder. I have a lot of scar tissue in my throat and the result is that it has contracted. My left arm hurts where the artery was removed. I have a lot of numbness around my wrist too. I had the operation to get rid of the cancer; I did not have chemotherapy or radiotherapy. I now follow a very strict programme.

19. Approximately four years following my diagnosis, in around 2004, I had the treatment for the hepatitis C. The hospital kept trying to get me to take it but I was just not ready. Things needed to be right in my life first so that I could cope with it, in case I got ill. I had to wait until my eldest two children were calm and stable after finding out that I had contracted hepatitis C. The intention was

to treat me with interferon and ribavirin for a period 12 months but I had to be taken of it after six months as I was so ill.

20. I faced no obstacles or difficulties getting the treatment; quite the opposite, I felt they were pushing it onto me.

21. Apparently they now test you to see how sensitive you are and depending on that they decide what treatment to give you. What I had was way too strong for my body to cope with.

22. The treatment made me totally lose myself both physically and mentally. I completely and utterly lost the plot. I spent every day lying on the settee, I was shaking inside, and it felt like my whole body was shaking. I was constantly throwing up. My hair fell out. I lost loads of weight; approximately two stone. I lived in my pyjamas. I crawled on my hands and knees to get around. I could not eat. It was like I was off my head on drugs; nothing made sense. My 14 year old daughter had to look after me, there was no-one else around to help. She had to cook for herself and do all the washing, shopping, cleaning and deal with the bills. I could not deal with anything. The only thing I did not have was an intention to commit suicide but I had everything else, every known symptom. I was a complete mess. I had the injections Monday, Wednesday and Fridays so that I could be a bit more with it to talk to my daughter at the weekends.

23. Yes, I do think my hepatitis C has impacted on my dental care in particular. I have to attend the dental hospital now. When I explain to any new dentist what an old dentist did to me in the past, they cannot believe it. I think I was given very poor treatment because they were paranoid of catching the infection.

24. I cannot be bothered having a relationship with a man any more. I have had relationships in the past and when I have told them that I have hepatitis C, they get paranoid and end up getting depressed and then I have to support them. It has been more hassle than it is worth. Some people in my family have been alright with it but I have found that when I have told people, I have had to

support them; I have had to manage their acceptance of it and reassure them that it is not as bad as it actually is otherwise they will not be able to cope with it. The hardest thing was telling my mum and dad, I have tried hard to protect them from the full force of the infection over the years. I still have a social life, but, it is limited and I do not tell people that I have hepatitis C; instead I tell them that I have ME. Now I can say I have had cancer and they leave me alone. I have had to get rid of some people out of my life especially where I have had to support them because it has become too much for me to bear. I do not have a lot of people coming around to the house any more. It tends to be just me or me and my children.

25. I have not told a lot of people because of the stigma associated with a diagnosis of hepatitis C. Even one doctor at the Hepatitis C Clinic where I was being treated asked me how long I had been clean for. Obviously, I was not happy about this, at the time I stormed out of his room. So I just tell most people that I have ME and cancer. One friend, who I did tell, refused to believe it. She would not accept that I had received the hepatitis C from infected blood given to me by the National Health Service, she said that it just would not happen.

26. There have been educational; work and financial related side effects too:

27. I have been in studies since I have been infected both before and after finding out I was infected, but I did find it very difficult. During the classes which took place one weekend per month I would have to take myself away to have a lie down. I found it difficult to concentrate and to hear people properly. In order to get through it, I would rest two days before the weekend, during the weekend for sleeps at lunchtime and then for two days afterwards.

28. I was infected with the virus at a young age. I have never worked properly; I have always been on benefits because I have not had the physical and mental capabilities to work. From the age of 17 all of my energy was going into raising my three children.

29. Financially, there have been times when we (my girls and I) have not had enough money to buy food and pay for the heating. I have gone without so many times so that my children are alright. I have had to beg a lot from charities. I had use a food bank; when I first moved onto Employment Support Allowance (ESA) and again when my Disability Living Allowance moved to PIP. My mum and dad have helped me numerous times with bills; I owe both of them thousands of pounds. At that time, they had to pay my rent as I had no money. I have always rented, I have never owned my own home anywhere. My rent is really high. I do not feel safe where I am.

30. The impact on those close to me has been very difficult to deal with.

31. When I first found out that I was hepatitis C positive, I had to tell my children. The eldest went totally off the rails and started getting into a lot of trouble where the police got involved and she messed up at school. My middle daughter started self-harming because she could not cope with the situation. My youngest has twice given up her life to care for me. She did this once without having a choice when she was 14 years old and I was on the interferon and ribavirin treatment and again after my discharge from hospital following the cancer operation; she gave up her career in London and her flat to come back to no money, no job, to nothing, to look after me. At that time she had no financial support at all, there was no help available for her. As she was a child we could not get carers allowance for her. I have since found out that she developed anxiety and depression during my hepatitis C treatment because she was very frightened I was going to die. She tried to hide it from me.

32. In relation to my parents, I think that the shock of finding out about my hepatitis C led to my father's death. My dad and I were very close; I spoke to him every day at 9.00am. We talked. He was very supportive to me but he felt so guilty. He was always apologising as if he had something to do with it. He found my infection too hard to talk about; it was unbearable. I really miss him. I have not been able to support my mum at times when she has needed me. I have been

too unwell. As I indicated above I have had to borrow money from my parents over the years, which has had an impact on them.

33. I pushed other family members away; I pushed them away as it was easier for me to deal with. Most cannot cope with how I am and I cannot cope with having to support them. The hepatitis C has meant that I have very little patience with people and I really struggle with this. I have gone through around six or seven different personal assistants, who were all friends or family and employed by social services over a ten year period. I have this help because I cannot cope around the home. Someone comes once per week for three hours. I was offered more hours of help but since I could not cope with sorting out the National Insurance and payments to the assistant; as I was employing them, the hours were taken away from me. Now another company sorts it out for me but the payments to me are less as a result.

Section 6: Treatment/Care/Support

34. I have faced difficulties and obstacles in obtaining care and support for years.

35. I have had no support or care. I should have had someone come to my home to look after me particularly when I was going through the treatment. I should have had someone every single day. I could do nothing. I needed this this help desperately badly. I was in such a state at the hospital that they took me off the treatment early so they knew what state I was in but yet they let me go home anyway. The hospital classed me having ME because they did not know what to do with me; they did not know where to put me. They did this because all the symptoms; the vomiting, the constant migraines had not gone away. My body was really, really heavy. To go to the toilet, I had roll of the settee, crawl up the stairs and come down on my backside. I was so exhausted I had to switch off the television because it would tire me out. I could not walk; I could not lift my legs. It took me two years to walk to the corner shop; I had to do it in stages. I had to work on myself, to get myself back together; it took me four years. It took me two years research how to help myself and what to do and it

took me another two years to put things into action. I have never had care or support for this when I desperately needed it.

36. Hepatitis C messes up your teeth, your gums bleed and your teeth fall out. I went to the GRO-D in Sheffield for treatment. I was talking about receiving some treatment; the man in charge of the department said something very hurtful to me. He came up to me and in a very hurtful and stern way said that he knew what the likes of me were up to. Like I was a benefits cheat. I felt totally humiliated. I was there begging for help because I was in such a bad physical condition, my teeth were in a terrible state because of the hepatitis C. I started to cry and he walked away. He made me feel like I was a drug addict. I already had a fear f dentists but he made that fear ten times worse. I avoid going and I should not because my teeth are in a mess.

37. I had some counselling just before treatment but it was only four sessions; it was too short, not enough at all and not the right kind. There was not enough feedback when I needed that interaction badly. I tried to go to a group of hepatitis C people, who were all newly infected people. It was a totally different story for them, they were not ill. When I had my cancer, I went to see the staff at the Hepatitis C Clinic; I told them that I needed someone to help me to sort my head out. The answer was no, we cannot help you because you are not on hepatitis C treatment. This was only one year ago. If I knew what the treatment did to me, I would never ever have had it. I regret having it. The treatment was horrendous and was unsuccessful. I still have hepatitis C.

Section 7: Financial Assistance

38. I have received financial assistance from Skipton, Caxton and England Infected Blood Support Scheme (EIBSS).

39. While I was on the treatment I was told about the Hepatitis C Trust and I think I found something on their website about the financial assistance that might be available. They were brilliant. They supported me. I cannot remember when I

found out that financial assistance was available but I researched it properly when I was well enough following my treatment.

40. From memory, I have received:

- £20,000 from the Skipton Fund in 2007;

- Financial support to move house and buy various household goods and appliances including a settee, beds, dishwasher, washing machine, bedroom furniture, laptop, car, respite breaks all from Caxton Fund starting in around 2009 until the Fund merged with EIBSS in 2018. The assistance was only given when I could prove I needed it;

- Financial support to pay debt accrued for things like gas, electric and council tax, from Caxton Fund from around 2009 until some time in 2017. They helped me with the payments from time to time only. It was only at the point at which I was threatened with Court action, and could prove it, that Caxton helped me;

- Financial support for me to visit my daughter at university in Newcastle which was provided in around 2011 by the Caxton Fund and for a period of approximately ten months;

- Financial support towards my daughter's rent at university while in Newcastle which was provided by the Caxton Fund in around 2011 for a period of approximately ten months;

- Stage One payments from Skipton Fund amounting to around £60 per week from 2017;

- Stage Two payments from EIBSS amounting to around £4,500 every quarter from around 2018;

- Special Category Mechanism (SCM) to top up my Stage Two payments which was paid by EIBSS and which started in around 2018. This amounts to £60 per week;

- Winter Fuel Allowance annually which is about £500 now but which used to be £300, and which started in around 2009. Caxton used to pay this money to me but now it is EIBSS.

41. The process of applying for Skipton was different to Caxton and was quite easy by comparison. The Hepatitis C Clinic at the hospital helped me to complete the Skipton form, they agreed with what I had written and signed it off. The payment arrived soon after. The Caxton Fund was entirely different. You had to apply separately for everything that you needed assistance with. I had show proof of my benefit and proof of income and expenditure. I had to send proof of Employment Support Allowance, Disability Living Allowance, rent, bills and bank statements. I found this really intrusive and was embarrassed by the pittance that I had. I will provide one example of how the Caxton application process worked. I applied for help with paying my daughter's rent during the first ten months of her university course. I wanted to do this to make sure she was safe because she has a severe nut allergy from which she has been hospitalised. I had to show different types of university properties to illustrate the differences in the price of accommodation; I had to send my daughter's tenancy agreement, proof of university, proof of loan and grant, medical proof of her nut allergy, medical proof of her eczema. I had to write a statement of why I was applying and how stressful the situation of her going to university was for me and for my daughter and why we needed the financial assistance. I had to write a lot of personal things in the statement, like the fact I was her only parent, how I was supporting her and how I am on benefits and how she had helped me when I was on the hepatitis C treatment and how close we are. This was all for approximately £40 per week over a period of ten months, £1,600 in total. When they made the payment they only paid one month at a time. They agreed to pay a certain amount and then I had to send proof that my daughter had received the money and that the letting agency had received the money. I

had to do those two things every month. Everything about the application process was so stressful particularly because I was so sick. I had to jump through hoops. I had no choice.

42. I think the above information covers the point but it is important just to say that as an ill person when I try to get help, the whole process of applying has made me more stressed and more sick. The process of applying for financial assistance has been a downward spiral for me. Unfortunately, because I was by myself and had no other financial support, I had no choice but to apply. It has been extremely stressful and I always made me feel like I was begging for help.

43. There might have been something that I had to sign for Skipton but it was so long ago I cannot remember. I recall vaguely that it might have had to do with not asking them for more money once you got the lump sum but I cannot really remember. For Caxton, before the money was sent, a yellow slip was sent, which you had a read and sign to say that the money would only be spent on the item you had applied for but this was strange as you had to send them a receipt anyway. When Caxton became EIBSS last year, I was so sick that I cannot remember whether or not I had to sign anything.

44. They left a lot of us in limbo for years, without any help. I think we should all have a massive lump sum to help make our lives the best that it can be for the time that is left, where you get the choice to do what you want with it. I think that there should be ongoing payments on top of that which should be at least £800 per week. This would then avoid the need for the stress that comes with applying for DLA, PIP, and Housing Benefit. There should not be a Stage One or Stage Two payment system. Stage Two payments along with Special Category Mechanism should be made available to everyone who has been infected. I also think that there should be something; nowhere near as much as for infected people, for affected people.

Section 8: Other Issues

45. I would like the Inquiry to provide answers and get to the bottom of this problem. I want the whole truth. I want the people responsible for this to be accountable. This problem needs to receive proper media attention and be placed into the public domain properly; the general public needs to be informed about this so that they understand it properly. People are in denial about it, because it is so bad they cannot believe it happened.

46. Back in 2007 when I first applied for Skipton, I went to the GP to get my medical records. The GP surgery did not allow me to look through my medical records by myself; I had to have someone in the room while I was looking through the records. I noticed that there was a period of time over approximately one and a half to two years, when my records were missing. It shocked me because this was the period during which I had my first baby and received the blood transfusion. I contacted Jessops Hospital a couple of months afterwards, the hospital where I had my first child and I was informed that there had been a flood and my records had disappeared in the flood. It surprised me that the very same records had disappeared. So there is no evidence of my first daughter being born. I am hoping that my solicitors will find some records for me and should they do so I would like to make a supplementary statement should it be necessary.

47. I feel that I have been treated quite badly as an infected person by my GP practice and by the Hepatitis C hospital. My doctor's surgery did not take me seriously about my throat cancer. My doctor at the GRO-D, in Sheffield for three years, I went back and forth to them with symptoms of cancer and they did not find it. I kept saying I'm coughing, I cannot breathe, sinus, ear ache. They totally missed it. In the end it was the dentist that discovered it. When I asked the doctor why she did not pick up the fact I had the cancer despite the fact that I had hepatitis C and cancer was a high risk to me, she told me that she could not pick everything up.

48. I feel like I have had to fight to be taken seriously and for investigations to take place. The Hepatitis C hospital seems to just want to pump me full of treatment. They don't seem to want to investigate what might be wrong with me, but just give me drugs. I have always felt that medics have just wanted me out of their office. Unfortunately, I very much feel like I have to play their game.

49. To put it mildly, I have no faith in doctors, no faith in hospitals, and no faith in any of them. After my cancer operation I had to have morphine. I was in the high dependency unit for six days. When I went to the normal ward they took the large trachea out of my throat to reinsert a smaller one. It ended up that I could not breathe. As a result of the way I have been treated over the years, I thought they were trying to kill me so I ripped the smaller trachea out of my mouth and tried to get out of the hospital. They gave me hepatitis C and when they tried to cure it, they made me worse. Is it any wonder why I thought they were trying to kill me?

Statement of Truth

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

Signed: GRO-B

Full Name: GRO-B

Date: 13 FEB 2019.