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Witness Name: Ms [GRO-B]

Statement No.: WITN2631001

Exhibits: WITN2631002 -

WITN2631007

Dated: 22 May 2019

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF [GRO-B]

Section 1: Introduction

1. My name is [GRO-B] My date of birth is [GRO-B] 1955. My address details are known to the Inquiry.
2. I live alone and have done since 2014. I no longer work.
3. I have been married twice. The first time was on [GRO-B] in Liverpool. This marriage broke down in 1995. I married for second time in [GRO-B] This marriage broke down in 2014. I have one daughter and three sons. My daughter is 42 years old. My first son is 39 years old; my second son is 37 years old and my third son is 35 years old this year.
4. I was born in [GRO-B] [GRO-B] is my first language. I came to England for the first time on 30 June 1980.

Section 2: How Infected

5. On the 15 May 1982 I visited Oxford Street Hospital in Liverpool for a pre-natal appointment. The gynaecologist that I saw decided to keep me in. On GRO-B 1982 I gave birth to my second son by caesarean section. I was given an epidural for the operation. Approximately 30 minutes following the caesarean operation; when I was back on the ward, I started to bleed. I was rushed back to the theatre. The gynaecologist tried to explain what was going on and what the medical team was going to do to help me. I was very upset and very scared because I did not understand what was happening, because of the language barrier, I did not understand what I was being told. I remember saying that I did not want to die. Just by chance a junior doctor was passing the theatre while I was in there; the gynaecologist and nurses shouted to him because they knew he spoke my language and they asked him to come to translate for them so I could know what was happening. This junior doctor told me that when I was stitched up from the caesarean, a blood vessel had burst and I needed to have my original wound re-opened to fix the problem. This doctor told me that I had lost four pints of blood and needed a blood transfusion and that if I did not have it, I would die. He explained that I also needed a general anaesthetic because I was so distressed. He asked me if I could consent to receiving the blood, he asked me if there were any religious reasons for me not having a transfusion and I said no. I remember the medical team putting pressure on the junior doctor to hurry up in giving the information to me. This doctor then left the theatre and left me with the medical team. I was given the blood immediately along with the general anaesthetic.
6. At the time of my blood transfusion, I was known as GRO-B. GRO-B was my nickname; the name made its way onto some of my medical records. GRO-B was my married name to my first husband.
7. I remember that when I came around on the ward, I looked up and saw on the black and white label on the bottle with the words 'Product of USA' written on it. My husband was there at the time and he said to me jokingly 'Oh you've got Yankee blood'. This became a joke between my visitors and me; they said that when the

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time came for me to be discharged home I would be speaking '*Yankee English*'.

8. I was not infected as a result of a relationship with another person.
9. When I was about to have the caesarean operation I was given a document to sign but I did not understand the information that was in it. The medical team gave the document to my husband for him to tell me to sign the document immediately, they told him to hurry up and get my consent. I did not know what was in the document until after the operation when my husband explained that I was required to sign it for the caesarean section covering the operation and the epidural. He did not mention a blood transfusion. When the junior doctor visited me after the caesarean and explained that I needed to have the blood transfusion, he did not explain that there was a risk of being exposed to infection. No-one explained that there was a risk. I do not believe that I signed a consent form before the transfusion and the anaesthetic were administered.
10. I was infected with hepatitis C only as a result of receiving a blood transfusion.
11. I was working as a HealthCare Assistant at GRO-B Hospital in 2005. During one of my shifts, I noticed that I was out of breath and struggling to get up the stairs. This was very unlike me. My work sent me to occupational health straight away. The doctor advised me to go to my GP and have a blood test taken. He told me I might be experiencing the menopause. I recall that I had also been feeling tired and restless. I got an appointment to see my GP at the GRO-B GRO-B the next day. My GP sent me for blood tests at the GRO-B Hospital. I had the bloods taken a short time later. I had to wait for approximately one week for the results. At that point my GP called me to say that I needed to come to the surgery to see her; she made an appointment for me.
12. When I went to see my GP, she asked me if I was sitting comfortably, she asked me if I wanted the bad news or the good news first. I said that I wanted the bad news first. She explained to me that when I had the blood transfusion in 1982; when I gave birth to my second son, that the transfusion I received had given me hepatitis C. I remember that I froze on the spot. As I was working in a hospital

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- environment, I knew what carrying hepatitis C meant. I had seen patients die from it. I asked the GP whether she was sure, she said yes. She told me that I had contracted hepatitis C from the blood transfusion. I remember that she told me that I was very lucky to have found out at that point because the damage to my liver was minimal and was only the size of a 50 pence piece. I do not know how she was able to tell me this at this point. The good news, she told me, was that I could receive treatment and on the National Health. She joked about the fact that they had poisoned me and so they might as well look after me now. She told me that I would not be working any more. I started to cry. She gave me a glass of water. She called the secretary to the liver specialist at Airedale Hospital for me to see him as soon as possible. An appointment was made to see him three days later.
13. The GP printed out some information from a website and told me to read it and she said that I would get more details when I saw the consultant. She explained that she could not tell me very much about it. I tried to read the information that she gave to me but I did not understand it, most of it was written in difficult medical language.
 14. I believe that I should have been informed in 1991; the authorities found out that the blood was infected in 1991. I remember seeing this on the television. At that time, I had no letter from the hospital, my GP told me nothing. No-one told me anything. If I had been told through a letter that I could have been infected I would have done something sooner. They have robbed me of some of my life; they robbed me of some of my dreams.
 15. I think that my GP dealt with telling me in the right way. She did her best. She gave me some information. She was direct. She tried to help me, she empathised with me; she gave me water. She told me she was so sorry. She said that I was going to have a hell of a journey. She was very professional, very kind and understanding. I found her to be better than the doctors at the hospital. She gave me some sleeping tablets just in case. She finally said that she hoped that everything would be alright for me.
 16. My hepatitis doctor at Airedale Hospital explained everything me, he explained the

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dos and the don'ts. He explained the risks of others becoming infected. I was told that I could infect others if I had a cut and I bled and another person came into contact with that blood. I was told to wear an apron and gloves at work and to cover any cut with a plaster. I mentioned to the doctor that I had given birth to a son after I received the transfusion. My son was born in 1984, two years after the blood transfusion. He told me to advise my son to have a test as soon as possible. He explained that the son I had just before the transfusion should be ok but that the son I had afterwards was at risk. My friend was with me during this appointment and he asked whether I was at risk of infecting others through sexual contact. The liver specialist had not mentioned this during the appointment. He said that it can be passed on by the smallest spot of blood. I was told to wear protection during intercourse. He advised me that my husband should have a blood test to check whether he had become infected. I was given a pile of leaflets with some information about the hepatitis and the risk of others becoming infected. I did not understand the information that was on the leaflet; again the information was much too medical for me even though I had worked in the profession.

Section 3: Other infections

17. I believe that I have been infected with hepatitis C only.

Section 4: Consent

18. I do not believe I was treated or tested without my knowledge or my consent but I do believe that I was treated without being given adequate or full information about the risk that there might be of receiving a blood transfusion. This is why I froze when the GP told me. I could not understand it.

19. I do not believe that I have been treated for the purposes of research.

Section 5: Impact

20. The impact of this virus on me has been significant.

21. As soon as I found out that I was infected with the hepatitis C I became depressed, I was crying all of the time, all day long. I then developed anxiety, within about three days of the depression. I was completely disturbed and developed insomnia and I became very fatigued. I got to the stage where I started to shut myself away. I was not eating properly and I was not sleeping properly. I was worried sick about my son in case I had given him a death sentence as well. I felt like killing myself. There were a couple of occasions when I sat on the bridge over a railway line and on the bridge over a canal where I was ready to jump and someone pulled me back. One man told me not to be so stupid; he thought I was on drugs. I told him that I had just found out that I was going to die and that I might as well go sooner as I was going to die anyway. From then on, I sank. I cannot get any lower. The physical effects have been numerous. I am tired and weak all of the time. I fall asleep many times during the day. As soon as I get up in the morning I am tired. I have constant chronic headaches which feel as if someone is squashing my head. Physically I can do nothing.
22. I have developed other medical problems and I do not know whether they are as a result of the hepatitis, as a result of the medication for it or for another reason. They include: acute cholecystitis, left ventricle hypertrophic cardiomyopathy and hypertension. Although it states in my medical records that this cardiomyopathy is an inherited cardiac condition, I am confused by this because my mum and dad did not have cardiomyopathy. My medical team did a gene test to see whether the cardiomyopathy was inherited from my mum or dad, but it came back negative. I understand they are undertaking further tests to see if the cardiomyopathy runs in my broader family. I have been told that I am a mystery to the profession; they cannot work out the cause. I had a stroke in 2016 and suffered a blood clot on my brain. This cannot be operated on because of my heart problems. I have been told that I am at high risk of death if I have a general anaesthetic. I have polyps on my colon which need to be removed and I need regular monitoring. I have gall stones. I have cataracts. I have a small hiatus hernia. My stomach is very swollen. I also get ulcers in my mouth and I have just found out that I have a cyst on my ovaries. I have to have a biopsy later this month.

23. Soon after my diagnosis, I started the treatment for the hepatitis C. I think that this was towards the end of 2005 or the start of 2006. I was given an injection pen with a medication inside called Interferon. I had to take this once per week along with between six and eight tablets per day of Ribavirin. I was also given a leaflet to read so that I could administer the drugs myself at home. I could not do this myself; I was supported through the treatment every week over the telephone by a lady who worked at The Hepatitis C Trust. I am very grateful for the support I was given. At the time of the treatment I was also given folic acid. I took the Interferon and Ribavirin medication for 48 weeks and sadly did not clear the virus. I was not able to receive further treatment for the hepatitis C because of my cardiomyopathy. In the years 2006 to 2015 I continued to test positive for hepatitis C. In October 2015 very surprisingly, my hepatitis C test revealed that the virus could no longer be detected in my blood, I think that the term used was that I was 'PCR' negative. In January 2016 I had another test to check this result and again the results revealed the virus could no longer be detected. **(WITN2631002)**. I do not know why or how this is the case. My doctor does not know how I cleared the virus; he even said to me that it was a mystery. In May 2016 I had an ultrasound scan done and there was no evidence of cirrhosis. I have been discharged by the liver clinic and am being followed up; at my insistence, on a three-monthly basis at my GP surgery where I have blood tests taken. I have noticed that on my medical records that in September 2018 I am referred to as having hepatitis C in my list of co-morbidities. **(WITN2631003)**. I think that this must refer to me having had the virus in the past.
24. Thankfully, I did not face any difficulties or obstacles in accessing the treatment for the hepatitis C other than having to go to the hospital to pick up the repeat prescriptions for it. I was only given one month's supply at a time. This was very difficult for me because I was so physically disabled by the condition which the treatment was making worse. I was told that more people required the medication than what the hospital had available to give and so it had to be rationed in this way.
25. I presume that I was given what I was entitled to, I do not know if there was something else that I could have or should have been given. I did not ask

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questions.

26. Other than the depression and the sleeplessness, I am unable properly to separate the impact that the hepatitis C has had from the impact that the medication has had on me. I do recall that there were some symptoms which I think were related to the treatment. I remember developing a brown patch all over my face which only disappeared when I finished the hepatitis C treatment. During the treatment I remember only being able to take two or three steps at a time when I would become so severely out of breath that I would have to hold onto walls for support otherwise I would have fallen down. I was yellow in colour and people used to laugh at me. I was called names by local children at a bus stop, names like '*ghostbuster*' and '*glow in the dark*'. This upset me terribly and I used to come home crying. The medication had a terrible impact on me and made my depression worse. I remember that I also developed really serious mood swings, most of my body hair fell out, my periods stopped, I was unable to eat properly and had to eat meal supplements, I became very forgetful and confused. My body completely changed.
27. I have found it difficult to get dental treatment since I was diagnosed with hepatitis C. I have only been treated once and that dentist was dressed like a he was in space when he treated me. I have had one dentist refuse to treat me; he sent me to a mobile dentist in a car park for treatment. I don't go any more, I cannot take it. When I visited Leeds Hospital for my gall bladder problem and I informed the staff that I had hepatitis C, they covered themselves in gowns before they came close to me.
28. The impact of being infected with hepatitis C on my private, family and social life has been tremendous. I lost my marriage; my husband walked out on me because he could not take it anymore. I believe that it was because he could no longer be physically intimate with me. Also, the side effects of the medication caused me to have such severe mood swings that I probably took them out on him. I was not able to be his wife properly. I had to sit down to clean and to cook; to do everything. My husband had to do everything himself. I lost my friends; they walked away from me. They got the impression that if they came anywhere near

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me that they would also catch the disease. I lost my family, my sons. They have kept away from me. They barely speak to me even now. They don't say that it is because of the hepatitis C but they give me the impression that it is. I have noticed they are different with me now.

29. My friends, family, work colleagues and potential employers have all repeatedly confused hepatitis C with HIV; I am asked constantly if I have AIDS, even in front of my colleagues. These colleagues all walked away from me when I was asked the question. I have been avoided and anything that I come into contact with has been discarded. The most difficult part about it is that during the treatment I was called horrible names. People have stopped coming to see me at my flat. I meet people in Liverpool instead. No-one has time for me anymore. I have suffered discrimination from everywhere and have been denied access to jobs and training that I have been over-qualified for as a result of my hepatitis C. I have even been told by the hospital staff to stop going to see them when I experience pain in my heart and not to waste their time. They have told me that my problems are gall bladder related and so I should not be going to the hospital for that, but, I am not able to tell whether I am suffering from problems with my heart or from problems with my gall bladder. I just feel very unwell. My cardiologist has said that I should still get an ambulance and go to the hospital because I cannot tell the difference in the pain but when I arrive there I am met with disdain.
30. There have been educational, work-related and financial impacts too.
31. I was told by my employers that it was a waste of time for me to go for nursing training as a result of the infection;
32. I can no longer work. I have been laid off since 2013. Between the years 2005 and 2013 I was in and out of work. When I started each new job I was given a new form to complete which asked if I had any infections. When I declared that I had, I was either sacked or told that the job was no longer available. The jobs that I managed to secure resulted in me being discriminated against and treated very unfairly in front of others. At a nursing home when I was employed as a care worker my

- role was changed after only two weeks to that of a cleaner, when the management discovered that I had hepatitis C. In the end I could not go for any work anymore. My consultant wrote a general letter for me which stated that I was not a risk to anyone (**WITN2631004**) but this had little effect;
33. Obviously, because I was unable to work, I had no money coming in and so I was eventually heavily burdened with debt. I had to turn to pay day loans and loan sharks to survive. This had an impact on my relationship with my husband too. I had no choice but to claim benefits. After a short period of time I was asked to attend medicals which consisted of an independent doctor assessing my health condition on behalf of the Job Centre. This doctor conducted two or three tests and did not listen to how I felt; this person did not want to find that I could not work and signed me off as fit for work. She refused to believe that I had hepatitis C; she insinuated that I was an alcoholic; she told me I looked really well and told me that alcoholics were all the same, implying that I was an alcoholic and that we were all trying to claim benefits. My benefits stopped straight away. No-one would employ me. I went to my GP as I was so depressed. I was in a very bad way. I was given medication and told to contact a mental health service. I was given a support worker who helped me to regain access to my benefits with the help of my MP. I am no longer being asked for medical evidence as I understand I belong to 'a group' but I do not know which group this is.
34. As I explained before, the impact on my private, family and social life has been immense. My marriage ended, my children don't bother with me anymore, and my parents are not alive. I am on my own here. Even my best friend died from cancer. I am here on my own and scared to die alone.

Section 6: Treatment/Care/Support

35. Other than having to go to the hospital for my repeat prescriptions for the hepatitis C treatment initially, I have not experienced obstacles in obtaining treatment, care and support in general. I have had problems with care and support from the local hospital. The hospital staff has treated me like I have a mental illness; like an

outcast, a nutcase. They have made my life extremely difficult.

36. Yes, I have been sent to a mental health centre by my GP for counselling and psychological support. This support has been adequate and I am happy with it. I am glad that the Centre recognises all of the things that have happened to me and what I have been through.

Section 7: Financial Assistance

37. I have received financial assistance from the Trusts and Funds set up to distribute payments.
38. When I started the medication for the hepatitis C in 2006, the nurse gave me the Skipton Forms. I applied straight away and was helped to do so by the GP and my consultant.
39. Skipton gave me £20,000 in around 2007. **(WITN2631005)**. After that, Skipton got in touch with me again and paid me a £500 winter fuel allowance each year. In 2007 Caxton took over the winter allowance. I cannot remember when I started getting monthly payments from the Skipton Fund but I believe it was in 2016 **(WITN2631006)**. I think the payments are made by the England Infected Blood Support Scheme (EIBSS) now. From April 2019 the annual value of my Stage 1 payments will increase to £4,006 per year plus the annual £531 winter fuel allowance payment.
40. My mental health foundation support worker helped me to fill out all of the forms for Skipton, Caxton and EIBSS.
41. I experienced no difficulties at all probably because I was given so much support by my mental health foundation support worker. The Trusts and Funds received all of the evidence they needed.
42. Skipton made me sign a document to say that I had received the money that they gave to me. I also recall that they wanted me to sign something that would not

allow me to discuss their support or complain about the National Health Service.

43. Caxton has been extremely helpful to me. When I got divorced they helped me to furnish my home with a carpet, washing machine, cooker, fridge freezer and bed. **(WITN2631007)**. This made my life so much easier. The money they give me now I put away for my funeral.

Section 8: Other issues

44. There are no other issues that I consider to be relevant to the Inquiry's investigation of the matters set out in its Terms of Reference that I wish to raise.
45. There are no documents that I wish to make the Inquiry aware of.
46. I would like the Inquiry to find out why I was not informed that I was infected. I was diagnosed by accident in 2005. I believe that those behind this knew that I had been given contaminated blood and so I should have been informed sooner.
47. Some of my medical records are missing. My consultant tried to get my records from Liverpool Maternity Hospital; which is the new name for the Oxford Street Hospital, where I had my second baby and where I received the blood transfusion which infected me in 1982. My consultant was trying to find evidence of my blood transfusion; I think it was to support my Skipton Fund application. It seems as though someone has physically removed the important evidence. There is evidence to say that I was haemorrhaging after my caesarean section and I was brought back to theatre. The second page of the letter is missing. It is my belief that the second page contained the information about the blood transfusion and that, this page was removed.
48. I would also like the Inquiry to identify those that are responsible this tragedy and to hold them accountable for what they have done to all of us; everyone that has been affected by this. I want them to realise what they have done. I have been robbed of my future. I might die at any time from a stroke. I don't have anything. I have nothing to look forward to. Each one of my siblings has made something of their

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lives; my brother and sister are both lawyers and another sister is a qualified nurse. It hurts me deeply to know that even though I have been in England all this time I have nothing to show for it. I should be something. I should be a fully qualified nurse. I have been robbed of my dreams. From 2005 until today I have been on the floor and people have kept me there. Most people have not helped. I am a shadow of my former self. I used to be bubbly person, a joker. I now feel worthless. I feel I am not wanted or needed. This is a deep feeling inside of me. The only person that I loved; left me because of this. All to do with this. The stress was too much for us both. Every day I feel sick, I cannot get up, I cannot walk, and I cannot do this or do that. I am prevented from living the life that I want to live. Imagine being called '*glow in the dark*'. I stopped going out because of the way I looked. I am only 63. This is not the life I expected for myself.

49. I have been forced to live in sheltered accommodation because of my condition. This is not where I would choose to be and I find it even more upsetting because I am the youngest person living in the building with other residents who are all 80 years plus. When a local nursing home closed down, all of the residents were moved here. I regularly see the ambulance arriving to take bodies away and it makes me think about my own life. This has a huge impact on me.

Statement of Truth

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

Signed: GRO-B

Full Name: GRO-B

Date: 22/5/2019.