Witness Name: **Shirley** GRO-B
Statement No: **WITN08130001**
Exhibits: **WITN08130002 -WITN08130005**
Dated: **5th February 2019**

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# INFECTED BLOOD INQUIRY

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## WRITTEN STATEMENT OF SHIRLEY GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30th January, 2019.

I, Shirley GRO-B will say as follows: -

## Section 1. Introduction

1. My name is name is Shirley GRO-B My date of birth is GRO-B 1959 and my address is known to the Inquiry. I am a retired civil servant, married with three adult children and a number of grandchildren. Within this statement I intend to speak about my infection with Hepatitis C (also referred to as HCV or Hep C). In particular, I will detail the nature of my illness, how it has affected me and impacted upon my family, and the treatment I have needed. I am currently considered 'clear' of this illness, although testing to monitor my status continues.

## Section 2. How Infected

2. I became infected with HCV in 1977 as a result of my receiving a blood transfusion at the Queen Mary's Hospital in Roehampton, South West London during an emergency caesarean section I underwent at the birth of my first child.

3. On the evening of the GRO-B 1977, when my baby was full term, I began bleeding. I was only 18 years old at the time. The baby had been due, but my waters had not yet broken and I had experienced no 'labour pains.' We did not have a 'phone in the flat my husband and I occupied at that time, and there were no mobile 'phones available, so there was some panic as my husband ran to a phone box to call the hospital.

4. I was suffering a substantial bleed, although I cannot quantify exactly how much I bled, so I ensured that I was lying down whilst awaiting help. The hospital told my husband not to worry, telling him that it was merely 'a show,' but I was bleeding too heavily for that, and sent him back to the 'phone as by then I was laying in a considerable pool of blood. This time, an ambulance was despatched to me.

5. The ambulance arrived slowly, without blue lights or sirens, and despite the fact that I was in a third floor flat, the crew waited for me to come down to them. They appear to have been told that my waters had broken, which was incorrect, but as my husband did not have English as a first language, I have to accept that something may have been 'lost in translation.'

6. However, once I made it clear that this was not the case (I was bleeding heavily as opposed to my waters having broken), they secured me to a trolley bed in the ambulance and took me to the maternity unit at Queen Mary's.

7. I was placed in a side-room of the maternity ward and the baby's heart was monitored, all whilst I continued to bleed out. I remember a nurse trying to prepare me for birth by shaving me, but she had some difficulty doing so, and kept having to wipe blood away.

8. My husband, who had been allowed to stay with me at that stage, noticed some apparent irregularity showing on the monitor - it had a 'bleep' which became irregular and occasionally stopped. It appeared to us that the baby's heart rate was fluctuating, stopping and starting. The lights and print out were not constantly beating so he alerted the nursing staff. As he did so, he was asked to leave the room.

9. I can't now remember how his having left made me feel, I was in physical distress, having a baby who appeared to be in distress, and was only concerned that my child be born safely. I may also have been given some medication to help me - possibly pethidin - but now, over 40 years later, don't recall all that happened, just parts.

10. I remember being told that as the baby was distressed, they wanted to perform a caesarean section to remove the child. They asked my permission whilst I was in the side-room. I can't now remember if I had been asked by the nursing staff or a doctor, but I was asked and knew what they intended to do for the baby and I, before they actually did it. They had also spoken to my husband before they spoke to me, and gained his agreement, but he can't now remember if he signed anything to that effect, or not.

11. Although I was young, I had a general understanding of what a caesarean section entailed. I don't recall having had to sign anything by way of consent, but in any event I gave my consent verbally and it was a dynamic environment with everything seeming to be happening very quickly.

12. I can't recall having been told of the manner in which the operation would be conducted, of any risks associated with it, or of any contingencies that may have been in place should things go wrong - in particular I have no recollection of my having been told that I may need to be given blood, by way of transfusion.

13. They still had not done anything to staunch the bleeding by this point in time. They simply kept wiping me up. No one completed any form of internal examination or broke my waters before I was taken through to the operating theatre for the caesarean procedure.

14. In any event, it was clear to me that this was to be an emergency procedure as they needed to get the baby out, so I gave them my consent. I know that I did this in the side-room, and may or may not have done so again when being taken to or into theatre, but I don't specifically recall.

15. From the side room, the next thing I remember was my being taken to theatre along a long corridor with bright lights above me, and then an anaesthetist being with me. I recall some anaesthetic having been spilled in my hair, making it very sticky. Some time later, I awoke in another side-room, possibly a theatre recovery room, with my husband beside me. I was then taken to a general ward which I shared with three other women. I had been placed on a saline drip post-surgery, and remained on one for a few days to rehydrate me.

16. I can remember sitting in that hospital bed afterwards, looking at a tiny white baby grow that we'd got for our child, and breaking down, thinking of how close I came to having lost my baby. I was so very grateful for the N.H.S. and for the medical team who helped us - and still am. Even now, when recalling what happened, I become tearful, upset, and find it difficult

to discuss.

17. At no point in time pre-caesarian do I recall having been told of the likelihood of my requiring a blood transfusion. Equally, I was not told that were I to need a blood transfusion, then that would itself carry its own risks. Accordingly, I never knew that I may have needed a blood transfusion whilst undergoing the procedure, or that I may be infected as a result. I simply didn't know, hadn't expected it, and only found out post-event.

18. Whilst recovering on the ward, once mobile again (I was confined to my bed for a few days), I inspected my notes - those kept on a clipboard style holder hanging on the bottom of my bed, and holding details of 'observations,' (temperature, blood pressure, etc). It was then that I read that I had been given a blood transfusion. I was not surprised to see this, as I had been bleeding heavily for an appreciable period pre-op', and had undergone a caesarian section. Had I been asked or told of the need, I would have consented, as it appears to have been necessary to save both of our lives.

19. I remember reading on the charts that I had been given 7 units or 7 pints of blood whilst in theatre. Whilst in the recovery room, and subsequently on the ward, I had received nothing more than saline.

20. My baby had been taken to special care baby unit for 48 hours. The child was jaundiced and had experienced a traumatic birth, but was otherwise healthy. I remained in hospital for just over a week.

21. I had suffered what is known as GRO-C GRO-C GRO-C It was a rare but natural occurrence that had not been picked up through pre-natal monitoring, including a

scan.

22. From the time of this birth in 1977, until 2018 - a period of some 41 years - I did not know that I had been infected as a result of contaminated blood having been given to me when I received those 7 units of blood during the caesarian section procedure. My husband and I found out by chance. In the interim, we had two other children, one born in 1979 and our third in 1994. We lived what is best described as a 'normal medical life.'

23. My husband went to see his General Practitioner in January 2018. He worked GRO-C and suffered a reaction to them which had historically been treated with a steroid cream. He suffered a further reaction, again on and around his hands and arms, and went back to see the doctor.

24. My husband rarely attended a doctors surgery, and generally speaking was, and is in good health, but due to his age at the time, and the fact that he hadn't been seen by a doctor for an appreciable period, the GP gave him a thorough check up. This included blood pressure and blood tests, as well as a liver function test. He had undertaken a well-man check when aged around fifty, and although he had not had a blood test on that occasion he had been found physically healthy with no cause for concern.

25. However, on this occasion, the blood tests revealed some abnormal liver functionality, and further tests were needed to determine exactly the cause. The possibility of fatty-liver was discussed as a potential cause. The further tests revealed that he actually had Hepatitis 'C' (HCV or Hep' C) and he was immediately referred to The Sheffield Hallam Teaching Hospital for specialist attention. He was then aged GRO-C

26. As a direct result of my husband's diagnosis, and the manner in which Hepatitis 'C' can be transferred from person-to-person, our doctor

suggested I was also tested for HCV. For the first time, our G.P. now also discussed with us the necessity of our having the children tested if my test proved positive.

27. Whilst discussing HCV, and talking through the various risk factors with our G.P., I mentioned to the doctor that I had received a blood transfusion in 1977. Although she didn't comment, I noticed that she immediately recognised something I had said, as her '*ears pricked up*.'

28. In February / March 2018, shortly after my husband, I found out that I also had HCV. I was also referred to Sheffield Hallam Teaching Hospital where they have a specialist infectious diseases centre by whom my husband was then being treated.

29. My husband and I always attend appointments together as, partnership aside, we feel that it helps to have someone else listening, in particular if there may be bad news and because English is not his first language. It was during his first hospital appointment that I again mentioned that I had had a blood transfusion in 1977, and was awaiting test results, but by that time, in my heart, I suspected that I had been infected and had passed it on.

30. Having confirmed that I too was infected, our three children were tested. My eldest child, the one born when I was given the transfusion, and our second child had not been infected. Unfortunately, although I understand that the chances of a mother infecting a child with HCV through birth are only around 5%, my youngest child was also found to have been infected.

31. All three of us have been treated at the specialist centre in Sheffield where our care and those caring for us have been fantastic.

32. Fortunately, we are a close family and speak to one another freely, so the children were then already aware of their fathers' diagnosis, and the conversation we had to have with them wasn't unduly difficult. Having said that, I cannot help but blame myself, for their having had to be tested, and although it was difficult to tell them that they needed to be tested, they had to be looked at as I may have passed on HCV to any one of them.

33. Whilst being tested by my G.P., I had been made fully aware of what I was being tested for. I knew that I was to undergo an HCV test together with a liver functionality test, and abdominal ultrasound scan as the liver is seriously affected by Hepatitis 'C'. The rationale for my being tested was fully explained by my G.P. and the hospital additionally tested me for HIV, vCJD, Hepatitis A and B.

34. During my husband's first hospital appointment the consultant nurse at Sheffield mentioned the Hepatitis Trust as a good source of information for us to learn more of our illness, as there was only so much time and information they could provide us with, in that time, themselves. They also provided us with a pamphlet providing Cirrhosis information. I looked online at 'NHS Choices' for information and this also led me to the Hepatitis Trust.

35. As I had only been tested as a consequence of our finding out that my husband had been infected, I was very aware of the possibility of my infecting other people. If I ever cut myself or anyone cut themselves around me I was very careful, something which may have appeared 'odd' to others, but not to me - I had to do this.

36. When I gave birth, I was just 18 years of age. I was clean living, married, and had seen my blood tested during the course of my pregnancy, with nothing untoward having been brought to my attention. I did not have HCV or any other blood borne virus. I have had no blood transfusions since. I

have used no blood products since. I have not engaged in any form of activity (e.g. sharing needles) that may have resulted in my becoming infected with HCV.

## Section 3. Other Infections

37. I was only infected with HCV, but have developed liver disease as a result. Whereas I am now 'clear' of HCV, my liver disease is regularly monitored for signs of improvement / further degeneration, and at the current time I have an adverse prognosis.

## Section 4. Consent

38. I did not know that I would require a blood transfusion. I was not told this, and only found out post-event by looking at my notes. At the time of the caesarian, I was unaware of any risks associated with the use of other peoples' blood and no one told me of any following the procedure. Some forty one years later, when being tested, I was able to provide informed consent to the relevant bodies as they had explained to me what they sought to do, how and to what end.

39. I have no reason to believe that I have been tested as part of some greater research project - my blood was tested merely to ascertain what, if anything, I may have been infected with, and to determine the best means of treating the same.

## Section 5. Impact

40. I did not notice any physical effects or symptoms of HCV from infection until diagnosis. I lived 'a normal life,' with my health placing no impediment before me. I was 'blissfully unaware' of my infected status until 2018.

41. With the benefit of hindsight, there was very little, physically to show that I may have been infected - I suffered from severe migraines, but thought that was just what they were, nothing else or signs of anything else. I had a number of bouts of depression for which I was clinically diagnosed and treated. At times, I became tearful, and felt that I had been a failure. However, I recognised depression and sought appropriate help.

42. My self-esteem had been extremely low throughout these periods. I was prescribed some relevant medication and attended Cognitive Behavioural Therapy (C.B.T.) to provide me with sufficient tools to notice any depression 'triggers,' and address my feelings. I have always associated my depression as having been an integral part of my coping or occasionally not coping very well, with life, and not any sign of HCV infection. I am not aware that it may be a symptom of HCV or liver disease.

43. The impact this has had on my mental well-being has been the worst. Depression aside, I am constantly thinking of what could have happened - it worries me that I could have passed on my infection to all three of my children; I felt ashamed that I had given it to my husband and youngest child, but had always known that it had not been "my fault," although that's how it *feels*.

44. I have much darker thoughts as well - I consider myself 'lucky' that I *only* had HCV - I think of what may have happened if I had contracted something else, such as HIV / AIDS or vCJD. I wouldn't have lived as I have, certainly wouldn't have had my children, and if I had, what would I have inflicted upon them, I could easily have been responsible for all of their deaths and that of my husband had I infected them.

45. The stigma associated with HIV / AIDS at that time was dreadful - I saw this whilst working for the civil service - and don't know how I would have coped with that. Again, I consider myself fortunate not to have been

diagnosed with anything worse, and then to have been diagnosed in 2018 and not 1977.

46. My family and I have been able to share our experiences and effectively established our own support group, to pick one another up when we need to. I now try to look at the positives, but still think the worst.

47. I worried that HCV medication wouldn't work - on my husband, on me, and in particular on my youngest child whom I had infected. Whereas all three of us are currently considered to be 'clear' of HCV, I can't help but doubt the longevity of the medication we received to cure us of it. What if it comes back?

48. Whereas I have said that the conversation my husband and I had with our children, encouraging them to have a test wasn't too difficult a thing to do, it was nevertheless an awful conversation for any parent to have with their children. It makes you feel guilty, sad, and angry.

49. Our two eldest children have families of their own - I am a grandmother - and my youngest child has a partner. Although the risk of my passing on HCV to my youngest was slim, it nevertheless happened. The thought of my having passed it on to my grandchildren worried me immensely, but fortunately neither of their parents, by me, were infected. Equally the partner of the child who had been infected had to be tested, but was fortunately clear. On each occasion I found the period of waiting between them being tested, and getting the results, an unbearably anxious time.

50. My husband and I were both put on Zepatier for a course of 3 months to clear the HCV. We were both clear at the 3-month test and I am going for my final 6-month test shortly. This will hopefully confirm the findings at three months post-treatment, but I do not know, and as the test date nears

I grow ever more anxious.

51. Luckily there were very few side effects of this treatment, other than my being more irritable than usual and suffering from excessive wind!

52. My husband and I both took Zepatier, through the specialist clinic in Sheffield. We would take regular tablets and they then tested our blood at 2, 4, 8 and 12 week stages throughout the treatment. We had to be accepted first - a matter which was questionable as a result of our liver disease, and I was worried that I may not be eligible, but they accepted me onto the programme. This was not 'experimental,' but a relatively new form of treatment being used for HCV sufferers who have Cirrhosis as well as HCV. At any stage along the treatment route, we could have been withdrawn from the programme in the event of a positive test being returned - fortunately we both passed unhindered. We then had to have our blood tested at 1, 3 and 6 months intervals. At the three month stage we were both declared 'clear.'

53. My youngest child was given a different drug to us as he had a healthy liver. This was just one large tablet, taken orally, once a day. It was a course of treatment of only two months duration, and the HCV cleared after just one course. He will now be discharged from the hospital.

54. As a result of my HCV, and the length of time over which it went undetected, my husband and I both have liver disease. We will therefore not be discharged from the hospital, and will continue to have to undertake scanning every six months for the rest of our lives.

55. These are ultra- sound scans and give me a lot of anxiety. I always find it stressful during a scan. Each time they slow down over a particular spot, I panic - thinking to myself 'what have they found,' 'what are they looking for,' and 'why are they taking their time?' I was last scanned in September,

it took longer than usual and really scared me. My next scan is due in March and I am already worrying about it.

56. Thankfully these appointments are only for an hour and a half each time, from beginning to end, and doctors go through the scan results with you, within that time, all on the same day - you don't have to go back.

57. I am usually a very open, conversational person, but with the HCV and Cirrhosis I have struggled to even voice my worries to my husband. I am always anxious and feel each and every 'twinge' of my body thinking it a sign for the worst. I cannot talk to others outside of my immediate family.

58. In my life, historically I did drink more alcohol than the recommended amount, something I saw and underwent as part and parcel of my working and social lifestyle, but it was normal to me and not excessive. Having HCV and liver disease makes people think that you are some sort of an 'alcoholic junkie' and I do not represent this, don't associate myself with this lifestyle and do not want people to think this of me.

59. I display some physical signs of Cirrhosis, which include skin blotches across my upper torso, and 'wonky' arthritic-looking fingers. I recognised these symptoms after reading a leaflet my husband had been given. It was very frightening, although I have had osteo-arthritis since I was twenty six - again not something I believed to be attributable to HCV infection.

60. As a result of my historic alcohol consumption (I no longer drink) and the longstanding undetected HCV, Cirrhosis of the liver in my case is more advanced. I am unsure at the moment how bad the liver is, however when I researched my Fibroscan results on the Hepatitis Trust website I saw that they equated my levels to end stage liver disease.

61. I am doing everything I can, including not drinking alcohol, and current liver function tests are all normal, with no 'red markers' showing. It was once

thought that liver scarring and Cirrhosis does not clear. However, as researchers are currently rethinking former medical evidence, I remain hopeful, but it nevertheless leaves me full of questions and fear.

62. Two years after the birth of my first child, I had my second child at the same hospital with no issues throughout. This birth had a scheduled delivery date due to the previous complications. Labour was induced and the theatre was ready, if needed, but I was able to deliver naturally.

63. That baby was healthy. My eldest had chicken pox at the time, so Queen Mary's kept us in a little longer than usual to keep the new baby safe, even though I was breastfeeding and likely giving the baby immunity (from Chicken Pox) this way. I was always given good care in this hospital.

64. With both of these births I was discharged with completed Shared Care Birth Cards. The investigator has taken a photo of these and I now produce them as my exhibits WITN08130002 and WITN08130003. Notably, with the first birth there was no mention of the transfusions I had received. The card only mentioned that there was a bleed causing foetal distress, it didn't even mention **GRO-C**

65. I was not given a card or anything else which advised me not to give blood as I had received a blood transfusion, or any other information regarding blood transfusions themselves.

66. I left St. Mary's Hospital (Roehampton) following the birth of my first child determined to become a blood donor - I had received seven units / pints of blood and wanted to at least give the same back. I was so grateful for what they had done for my child and I that I wanted to ensure I gave this amount of blood back.

67. I gave blood twice, and after a short break, during which I had my second child, returned to give blood for a third time on 12th January 1983. I donated blood, as usual, and left the blood donor site afterwards.

68. A few days later, I received a letter informing me that testing of the blood I had given (12.1.1983) had returned test results showing my blood contained Anti-E antibodies but they were insufficient to use in making make serums, and that I could therefore not give blood anymore. I was very disappointed not to be able to return the blood I had been given.

69. It didn't mention any infection(s) I may have had at that time, but I do not know whether or not they would have been able to test for HCV at that time. I received a card with the letter, showing my blood contained these anti-bodies in red ink, a card I was advised to carry with me at all times, and to show to doctors / dentists if I was ever admitted to hospital or had to undergo surgery. A copy of this item I now produce as my Exhibit WITN08130004.

70. I took this document to the Blood Transfusion Service in Sheffield in the mid 1990's, to see if I could then give blood again, but I remained 'barred' from doing so. They told me that the presence of Anti-E antibodies was a common occurrence post-transfusion, so I did not think any more of it at the time.

71. Post diagnosis (with HCV) the concept of my infecting someone else was ever-present. Internally I felt manic, always trying to ensure I was careful. I knew it was a very narrow risk, but I had infected my own child at birth, so I was very conscious of the possibility. I look after my grandchildren at least twice a week, and was scared.

72. After a childhood of tonsillitis and numerous Quinsy's (throat abscesses), I had my tonsils removed in March / April 1991, aged 32, at St George's

Hospital in Tooting. I have also had some wisdom teeth extracted. As far as I am aware, I was not given a blood test for either of these procedures, and equally know that I received no blood as a result.

73. In 1994, sixteen and a half years after my first child, I gave birth to my third baby. I had my blood tested throughout this pregnancy and nothing untoward was detected. Despite some signs of spotting, I had a relatively simple, natural labour. The baby was born in the Royal Chesterfield Hospital.

74. The child was born with some muscle shakes and was slightly jaundiced but this did not appear to cause any particular concern to the medical staff at the time, and we returned home. The baby was kept in the hospital a little longer than may have otherwise been the case, due to its shaking, but it had dissipated before the child was released. Both my second and third children have also suffered from excema, and continue to do so.

75. I had no real health issues up until 2014 when I was diagnosed with Type 2 diabetes. This I have been managing by diet, as I was only just in the diabetic range - my diagnosis having been marginal.

76. It is interesting to note that my levels of diabetes have decreased to below being clinically diabetic since completing my HCV treatment with the new drug, but I remain 'under the doctors' for diabetes monitoring.

77. My private life has been affected by HCV. Luckily within my family we were able to be open, but I did not want to tell anyone until I knew I no longer had the illness. I worked in a local charity shop and my boss, a friend in whom I confided, was very understanding and let me have time to go to all necessary appointments. Other employers may not have been so understanding, but I feel that the work of the inquiry is helping to spread understanding.

78. When the Infected Blood Inquiry commenced, and was publicised, I used this as an opportunity for me to 'come out' to particular people, people who would not jump to conclusions as to my lifestyle, for example. The more I have opened up, the less concerned I have become as to my being overheard talking about it.

79. As I had already retired when diagnosed with HCV, I do not think the infection impacted upon my employment / employability to any great extent. I had previously enjoyed a good career in the Civil Service.

## Section 6. Treatment/Care/Support

80. I have not faced many difficulties in obtaining treatment. In order to be given Zepatier, for HCV, I had to be accepted by a board before they would agree to my treatment, but I was accepted notwithstanding my liver disease.

81. In terms of psychological support, my husband and I were each provided with a number for a helpline, and / or the opportunity of using a counselling service, if necessary by the hospital in Sheffield. At the moment we have not needed it. We have a mutual support group in our family. We are all open and honest with each other and can support each other when we need to.

82. I am aware of the helplines available through the inquiry operated by the British Red Cross.

## Section 7. Financial Assistance

83. When I was researching HCV on the Hepatitis Trust website, I found information about EIBSS financial assistance. As a result of my research I

saw that historically there had been a number of other schemes such as 'Skipton' but I had not engaged with any of them. I approached the EIBSS.

84. I have received both Stage 1 and 2 payments. My husband has chosen not to apply for any assistance. My youngest has been approved for Stage 1 payments also.

85. The process of applying for assistance is fairly laboured, requiring a lengthy form being completed. As an ex-Civil Servant, I know how forms and processes work, so personally I was able to provide as much information as I possibly could, knowing that they would need as much evidence as possible. This included information about benefits and income, by way of examples.

86. There was a delay of a few months and the EIBSS were not great at keeping an applicant informed of progress, but payments are backdated to the time of your application, so any delay does not affect you in the long-term.

87. My Stage 2 payments took some time before they were approved. When I looked into this it appeared that they were initially going to reject my application, however they decided to review their own internal decision and it was subsequently approved.

88. Sheffield Hospital supported me on both applications and my G.P. was willing to support me, had I required any further assistance.

89. I was lucky in that I had some evidence of my transfusion as this would have made the process harder. My documents from Queen Mary's had apparently been destroyed, as I had not been treated there for over twenty years. My G.P. gave me a copy of my full medical notes without

charging me.

90. I believe that the work of the Inquiry helped them to be expedient as the EIBSS are aware they are potentially being 'looked at' as an integral part of the inquiry process.

91. EIBSS money has really helped us. The Stage 2 payments in particular, have enabled us to feel financially 'comfortable.'

## Section 8. Other Issues

92. I feel extremely lucky to have received the NHS treatment that I have. This is both in saving mine and my baby's life in 1977 and in the care and support I have experienced in the last year with my diagnosis and treatment.

93. I am grateful, in a way, that we found out when we did, and that the medication was as modern as possible. I have heard stories about people in similar positions to myself, who were on different treatments which simply served to make their lives worse. Also, I am aware that an appreciable number of people, women who received blood transfusions in childbirth - after I did - have since passed away as a result of their having been infected.

94. I had never met anyone else who had HCV before the inquiry started, save for my husband and youngest child, not even at the hospital where everyone is treated anonymously. The Infected Blood Inquiry's engagement meetings have allowed me to do this, which has been for the best in my case, and I no longer feel so alone and isolated.

95. I additionally provide, as exhibits, copies of my medical record showing I suffered a 'Placenta Abruption' and that I had been 'transfused 4.0' or

'transfused 40' (the former shown above a section of darker script, the latter below it) - WITN08130005.

**Statement of Truth**

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

**GRO-B**

Signed: **GRO-C** **GRO-B**

Dated: 5th February, 2019.