

Witness Name: Raymond Smith

Statement No.: WITN0046001

Exhibits: WITN0046002,

WITN0046003, WITN0046004

Dated: 24.01.2019

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF RAYMOND SMITH**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 19<sup>th</sup> December 2018.

I, Raymond Smith will say as follows: -

#### **Section 1. Introduction**

1. My name is Raymond Smith. My date of birth and address are known to the Inquiry. I am the husband of Linda Susan Smith and the father of our two children Faith Richardson and Luke Smith. Linda and I were married in July 1974. Linda is a qualified teacher and has taught throughout our married life. Linda took early retirement on an actuality reduced pension in December 2010.
2. In this statement I intend to speak about my wife Linda and her infection with the Hepatitis C virus (hereinafter referred to as 'HCV') from contaminated blood given to her during a blood transfusion. I will go on to describe in particular, the nature of her illness. how her illness affected me and my family, the treatment which Linda received and the impact it had on her and our lives together.

**Section 2. How Affected**

3. Prior to the birth of our first child Linda was an extremely active member of our church, participating in many meetings and teaching in Sunday school. She was also a qualified football referee. Linda was in excellent health and able to donate blood. GRO-C  
GRO-C
4. On GRO-C 1982 Linda gave birth following a difficult pregnancy, to our first child, Faith, at Doncaster Royal Infirmary (DRI). Linda suffered a serious haemorrhage and following the birth she was in theatre for six hours. At that time I was working at the hospital as a HCO in charge of the medical supply stores and I was called to the delivery suite where I was informed that a blood transfusion was urgently needed.
5. Linda was not in a fit state to sign the consent forms so I signed them on her behalf. Linda was given six units of blood. I was given no information or advice regarding any exposure to infections beforehand, just the necessity to save her life, which it did.
6. I believe that the blood transfusion saved Linda's life but at the same time, as we later discovered, unbeknown to either of us this blood transfusion also infected Linda with HCV.
7. Linda returned to the ward once she was stabilised, still with various tubes attached these were removed over a few days as Linda recovered. Linda and Faith were discharged into domiciliary midwifery care at nine days.
8. After leaving hospital there appeared to be no apparent medical problems save for a case of shingles in May 1982 which was put down

to the problem pregnancy but we noticed that during the summer of 1982 Linda did not tan which was unusual. Linda also said she felt sure something was wrong after the blood transfusion but several tests for various things including HIV showed up negative. The only thing that showed up was a very low haemoglobin count but as she was not ill this was put down as her norm though this had not been apparent before.

9. Linda always said something changed after the birth but nothing appeared to show up in any blood tests apart from the low haemoglobin count which showed up when she went to be a blood donor. The National Blood Transfusion Service referred her to our GP who put her on iron tablets which made her really poorly with side effects of diarrhoea and vomiting. The GP took her off these as she was not ill prior to being put on these. Linda even queried HIV with the GP.
10. In March 2002 Linda collapsed at home and she was admitted to DRI for five days and given lots of tests and x-rays. These also included some further out patient tests, GRO-C and scans. Linda was discharged with no known cause found. The tests undertaken should be recorded on her medical records.
11. Four years after the birth of Faith our son Luke was born. He was born on the GRO-C 1986.
12. Apart from the above Linda did not seem to have any health problems apart from another case of shingles and suspected mumps. Again, these details should be recorded on her GP records.
13. It wasn't until June 2003 that we found out that Linda had been infected with HCV. Linda and myself gave blood at a pop-up donation centre at Danum Road, Doncaster in May 2003. This was unusual as Linda had always been rejected by her low haemoglobin count.

14. Linda received a letter dated 2<sup>nd</sup> June 20013 which arrived in the post open and unstamped from the National Blood Service based in Sheffield. My initial thought on receiving the letter was that at last Linda had received a service badge as I had some time earlier.
15. The letter was addressed to Linda and signed on behalf of Dr N Hewson who appeared to be in a team led by Dr V James, Consultant Haematologist. The letter confirmed that Linda's blood donation had been tested as a matter of course and found to be positive for the Hepatitis C infection. I have provided a copy of this letter to the Inquiry which I refer to as Exhibit WITN0046002.
16. Dr Hewson confirmed that some donors could have health problems and they asked Linda to refrain from donating blood or plasma for the time being and not to carry an organ donor card. The letter confirmed that they knew that the HCV was transmitted by blood. Linda was advised to seek specialist advice and to get in touch to have a repeat blood test. Linda was also urged to get in contact with the National Blood Service to discuss further.
17. After the initial shock we were horrified that such a letter was sent unsealed and unstamped and with no prior warning or medical help. Linda rang the GP surgery and spoke to a nurse, who was just leaving, who helped to calm her down.
18. The letter caused us considerable fear and panic. After our evening meal I hit the internet and from what I found there caused us both a sleepless night consoling Linda through the tears.
19. At 9:00am the next morning we contacted the National Blood Service based at Longley Lane Sheffield S57JN. Later that day an appointment was arranged for the following week. Consequently, we had a further

week of worry, tears and sleepless nights. I did not feel adequate information was provided to me or Linda during this time to understand and manage the infection. I feel that we should have been informed of the infection when the powers that be knew that Linda had received contaminated blood.

20. We saw Dr GRO-D at the National Blood Service on the 10<sup>th</sup> June 2003. Linda was confirmed as Hepatitis C positive.
21. I feel that the way we were dealt with at that meeting was diabolical as it was assumed that Linda was responsible for the infection. There was the suggestion that she had had multiple partners, tried drugs, had body piercings or injected drugs. I am aware these things have to be ruled out but by the way these questions were put it left us both devastated. We are both Christians and we attend a local church.
22. We had to remind him that Linda had received a blood transfusion following her difficult pregnancy. The attitude of the doctor did change at this point and the Doctor queried how many units Linda had received in theatre. We said six as we had seen the stickers from the bags on her records. Linda had attended many gynaecology clinics and Linda and I had seen these records. It was at these meetings Linda had queried why she was feeling different following the blood transfusion.
23. Linda was told to use rubber gloves when dealing with poorly or injured children, which she had always done as a matter of course following her training on First aid courses. Linda was and still is a trained first aider.
24. Linda queried whether I was infected and we were simply told to use precautions. As I had also donated blood with Linda we knew I was not infected at that time. When we asked if I would be re-tested the answer was "No!".

25. When Linda then asked if it could ever be proved that I had not been infected in the past six weeks, since I had donated blood, the doctor simply shrugged. Linda and I were both devastated by his body language but even more so when we asked about our son, who was born after the blood transfusion. The doctor was more concerned about our daughter Faith who had been in the nursery whilst Linda was in theatre, and therefore, safe from infection. We again queried about Luke and were advised to take him to the STD clinic, a totally unsuitable place for an innocent teenager. Linda tearfully told him that Luke was under age and if she took him, she could lose her job if she was recognised.
26. We were told we had a duty of care to inform our GP and Dentist about the diagnosis of HCV. Linda was then referred to The Royal Hallamshire Hospital (hereinafter referred to as 'Hallamshire Hospital') in Sheffield.
27. Having had this diagnosis confirmed lots of thoughts went through both our minds. I wondered where Linda had contracted HCV and if it was connected to the blood transfusion she had received in 1982. I wondered if Luke or I were contaminated. I questioned what I had done by signing the consent form. I was concerned whether Linda would be able to drive us home after our meeting. I wanted to know if Linda would die. I wanted to know if she would still be alive at Christmas. I wondered if she would live to see Faith married. I wondered how we would tell Linda's parents and other family members, friends and colleagues. Many of these thoughts Linda also shared with me. She then had to drive us both home as I cannot drive. I still don't know how we got home that evening.

### **Section 3. Other Infections**

28. I do not believe Linda received any other infections other than HCV as a result of the blood transfusion she received after the birth of our daughter.

### **Section 4. Consent**

29. I signed the consent form for permission for the blood transfusions as Linda was not fully conscious at that time. I understood the seriousness of the situation and I had no hesitation in signing to save Linda's life. When Linda started her HCV treatment Linda was asked to sign a form which contained a section asking her if she agreed for to be part of research to which she agreed. The treatment was to take place at Hallamshire Hospital.

### Section 5. Impact

30. The stigma attached to this illness meant that neither Linda or I could discuss this at church. We were advised to only tell people who could help us through it. Many of our closest friends could not cope with the knowledge. Many of those people Linda felt able to tell told us they didn't sleep the first night as they thought over what she had told them. A few friends would not touch Linda after being told. Linda would say that she felt as though she had 'the plague'. People asked lots of questions to which we had no answer. Some were devastated at an innocent person being infected this way.
31. Prior to beginning treatment, Linda's colleagues and the parents of children in her class often queried the amount of time she spent at hospital appointments when she did not appear ill.
32. Linda called it the "Princess Diana syndrome" with the HIV babies. We became very wary of telling people. Linda had to tell some colleagues who were working with her of the diagnosis of HCV as she had so many hospital appointments and did not appear ill. This caused us a lot of stress, trauma, tears and heartache.
33. Telling Linda's aged parents was a nightmare as they were so far away in Kent a 260 mile journey and we had to travel there to do this. Linda was due to have her first liver biopsy. We needed to inform Linda's

parents as the biopsy was now arranged. The hospital agreed they needed to know in case hospital arrangement occurred in school holidays and we would be unable to visit them.

34. GRO-C it was agreed that we would tell her father first. Linda took her dad for a walk while I looked after her mother. Her father was devastated and tearful and wanted to know what would happen next. Her mother became aware that something was wrong and became very agitated. On their return we all told Linda's mother what had happened and what would happen next to the best of our knowledge. Both parents were extremely distressed especially having been told they could not talk about it to their friends as we had already seen the effects it had on others. Like us they received no counselling. Many questions were asked both then and later over the phone.
35. Upon being referred to Hallamshire Hospital Linda had a long appointment with a male nurse practitioner. He was extremely professional and caring, who told Linda what would happen next and warned her of how others might react. Once again, Linda was asked about drugs, tattoos, piercings and partners but this was never queried again. Having been through this at the transfusion centre we were a little more prepared for these questions but it was still distressing to have to go through them again.
36. Linda asked the same nurse practitioner about getting Luke checked because of his age and she was told to ask our GP to refer him to Hallamshire Hospital for testing. This was done later that year along with counselling from the same nurse practitioner.
37. Luke was aged 17 when we received the initial letter notifying us of the suspected HCV diagnosis. We kept him informed throughout and he assumed his mother was going to die and at that time we couldn't help because we also had no answers. Luke was concerned about having a girlfriend and a future family if he was confirmed Hepatitis C positive.



Both Linda and I were distraught with what we had to put Luke through. Fortunately Luke tested negative in October 2003 to every one's relief but it didn't alter his thinking that Linda was about to die.

38. In June 2003 Faith was in her final year at university waiting to graduate and get married in July. With Faith we took the decision to wait until she got home and tell her face to face. When we told her she sobbed, agreed we had made the right decision and could see Linda was sort of ok. We all cried, were heartbroken and Faith had lots of questions, including would Linda make it to her Graduation and wedding and how long Linda had to live. Faith was convinced this was a death sentence. Faith was extremely concerned how she would tell her fiancé Jonathan.
39. Commencing in 2003 Linda had six monthly hospital appointments at Hallamshire Hospital which often resulted in sleepless nights the night before going. Linda always went with a list of questions, which were always answered forthrightly. I also made sure she did not go to these sessions alone. If I was unable to go, I always ensured she was accompanied on these visits.
40. I always accompanied Linda on these routine six monthly visits and sat in on the consultations except once when I was ill. A close friend, retired, from church had offered to accompany Linda on any occasion should there be a need. He understood the condition and Linda's emotional needs. On this occasion with only half an hour notice he went with Linda to her appointment but stayed in the waiting room during her appointment.
41. Every three years Linda had to have a liver biopsy to assess any liver damage. My first concern was getting Linda to and from these appointments as Linda was not allowed to drive following the procedure. In 2003, a husband of one of Linda's teaching colleagues who worked in

Sheffield took Linda and I to the appointment and waited to collect us when the hospital discharged Linda. My feelings on this and all occasions was what the doctors might find and what would be the implication of any findings.

42. Unfortunately, the hospital clinicians took no notice of Linda or her notes regarding a severe allergy to any kind of plasters. This almost resulted in Linda not being discharged due to a severe reaction. Luke was living at home at this time and lived with us through our anxiety. Faith was married by this time and had an anxious day at work and was waiting for us to phone when we got home. Linda went back to school the next day heavily bandaged.
43. In 2006 a friend from church who worked in Sheffield took Linda and I for her second biopsy. Our feelings on this occasion were similar to the first time but now they had a 'control' picture of Linda's liver to compare it to. This time Linda's head teacher insisted she asked for a sick note after the bandaging of the time before and working with such young children.
44. Routine hospital appointments continued at Hallamshire Hospital until it was decided that a suitable treatment was viable for Linda as she seemed to have no serious ailments from the infection. I do not believe there were any further medical complications or conditions which resulted from HCV. I feel that the treatment plan offered was thoroughly discussed with Linda and with myself present so we knew what to expect.
45. I do not feel that Linda faced any particular difficulties in accessing treatment other than getting to and from her hospital appointments as I was not able to drive due to an eye condition.

46. In September 2009 Linda commenced HCV treatment with Interferon. This involved administering one injection per week and taking tablets daily.
47. The nurses recommended that Linda drive from Doncaster to Meadowhall, a shopping mall in Sheffield and park there as parking anywhere near Hallamshire hospital was a nightmare. Linda would then take a tram trip followed by a walk up the steep hill to the hospital. This became much more difficult for Linda as her treatment progressed. It was particularly difficult during the winter months where there were ice and snow conditions and tram derailment's which didn't help. We would usually leave home at 8:00am and arrive in time for Linda's appointment at 10:30am. We chose this appointment time to enable me to use my bus pass on the tram to keep costs down.
48. One Winter morning, after a tram derailment caused delays we had to rearrange our journey. Phone calls to the hospital department (Communicable Diseases Directorate) told us the appointment would remain open and to get there when we could. This caused us more expense in both train and bus journeys.
49. Linda suffered fatigue, loss of appetite, hair loss and the Monday trauma of injecting herself. There was little or no counselling options available locally to help her during her treatment. Linda was on a waiting list for counselling closer to home in Doncaster but the waiting list was so long it would have taken place after she had finished the treatment. Linda therefore agreed to the counselling service offered at the Hallamshire Hospital.
50. Linda received counselling from Dr. Jo Nicholson, Clinical Psychologist working in the Communicable Diseases Department at the South Yorkshire Regional Department of Infection and Tropical Medicine at Hallamshire Hospital. Linda needed the counselling. I have provided to the Inquiry, a copy of the letter from Hallamshire Hospital which I refer

to as Exhibit WITN0046003. This letter explains the circumstances and need for counselling. I have also provided to the Inquiry a copy of the letter from the Community Mental Health Team based in Doncaster which I refer to as Exhibit WITN0046004. The letter was dated 13 January 2010 and Linda had already started and nearly completed her treatment.

51. Linda took some time off work until things got too bad. Around week 20 of her treatment, in January 2010, Linda was forced to go on long term sick leave. Despite being extremely fatigued and not well enough to go to work Linda was still doing planning for her class being devastated by the fact she was letting both the school and the children down. She did appreciate the fact that she was not fit for work but that did not stop her fretting about 'her children'. She was concerned that she might not be fit for work again.
52. By week 20 Linda wasn't sleeping and she was prescribed sleeping tablets to take twice weekly. I would often find Linda downstairs watching BBC News for company where she had often been sitting since 2:00am.
53. During Linda's treatment period, the impact and effect on the family was traumatic, trying to cook meals she was able to eat, helping her up and down the stairs and making sure at least one of us was close by when she was in the shower. I even had to put her shoes on and fasten her boots by the end of treatment.
54. We managed between us to always have someone at home. Faith was living with us in February 2009 as she now had a job in Sheffield. If she was able to change shifts or rearrange her shift pattern she would meet Linda at Meadowhall and accompany her to her appointment and then drive her home. I would normally go with Linda as I only worked part time two days each week for four hour at Sainsburys.

55. I always made sure I knew where Linda was. The hospital had recommended that Linda drink three litres of water per day and I always checked she had enough to drink and enough to eat. I made sure she was able to get to her various appointments. It was difficult for me to cope as I had to encourage Linda to eat throughout the treatment. Just after Christmas 2009 [GRO-C] which was very painful and she could only manage ice cream and yoghurt for about three or four days.
56. During the latter stages of treatment especially Linda could not cope with visitors other than family. She just sat on the sofa either napping or 'watching' TV. She had very little energy or enthusiasm for life. This was most unlike Linda who was normally full of life. I didn't have any private life. My time was taken up with caring for Linda especially through the latter stages of treatment. There was the rare good day but these were few and far between during this time. Also during this time we were helping Luke prepare for his wedding.
57. Linda had normally been a busy and active person both as a teacher and a Christian involved in our church. I love my wife and it was hard to watch her go downhill so rapidly whilst on treatment. Our family tried to console Linda over her hair loss and personal care along with the other side effects of this treatment which at times was quite debilitating.
58. Whilst Linda was on her treatment plan we had no social life, Linda wasn't eating properly and was unable to cope with company. Our children were constantly on the telephone or visiting and were extremely concerned for both Linda and myself. As Christians, one of the hardest things was not being able to share or ask for prayer from the church for hospital appointments and treatment as we had found those we had approached were unable to understand. As a result of this many people were not aware of how ill Linda was whilst she was on this treatment.

59. We notified our dentist of Linda's diagnosis. Our dentist was very concerned as to how to deal with an HCV patient. Linda was always given the last appointment of the day so that they could deep clean the surgery. Linda felt the dentist really understood what was wrong with her and again Linda felt like she 'had the plague'. This was a phrase she often used to explain peoples negative reaction. Even now she is still ill at ease when she attends the dentist. I also took Linda to an eye appointment at Hallamshire Hospital in November 2009 at which there were no problems.
60. The only real problem was one occasion when Linda rang the Group Practice for a sick note. Linda's GP had recorded her as having a viral infection on previous occasions when he issued Linda with sick notes. On this particular occasion the GP insisted on writing Hepatitis on her sick note. Linda sobbed uncontrollably and I contacted Hallamshire Hospital who telephoned the Group Practice and reminded them that there was a risk to Linda's job should this be submitted.
61. Linda was absolutely devastated. She was told that the Doctor could not lie. Linda explained that she was not asking him to lie, just not to use the Hepatitis word on her sick note. The Hallamshire Hospital staff were also very upset about the distress caused by the sick note so they rang the GP surgery to help me sort this out. Linda even threatened to go back to work even though she was actually not well enough health wise or emotionally. I don't know who the Hallamshire team spoke to but the sick note was changed to sort it out. Owing to this trauma I feel Linda went back to work too soon.
62. Linda had trouble obtaining a flu injection through her GP in the winter of 2009 following her treatment. Linda was told she didn't meet any of the criteria. The Hallamshire Hospital medical team, The Communicable Diseases Directorate sorted it out with the GP in January 2010.

63. Linda had learned of her infection with HCV just before Faith was to be married which completely spoiled what should have been a very joyous occasion. Linda completed her treatment just before Luke was married so she was still suffering from its side effects of fatigue, listlessness and hair loss. Linda's hairdresser noticed early in the treatment how damaged her hair had become so that it appeared burnt. Staff at Hallamshire Hospital recommended Linda wear a warm hat and coat to keep her comfortable. We purchased a long warm purple coat and black furry hat for her.
64. Linda wasn't really well enough to enjoy Luke's happy wedding occasion as well. Linda's father, brother and sister-in-law were able to realise just how ill she had been and were totally devastated by her condition. Linda's father, who had also very ill and hadn't seen Linda during her treatment was shocked by her appearance, her brother and sister in law were unaware of her condition or treatment so all spent an hour in a hotel room explaining.
65. Linda was on treatment for 22 weeks up until late January 2010 before her treatment was stopped. The course was supposed to be 26 weeks. The treatment was terminated after Linda was admitted to Doncaster Royal infirmary after I found her in a state of collapse in the bathroom at 2:00am in the morning.
66. I was unable to get any response from Linda so rang for an ambulance. Linda was taken to A&E at the DRI with her bag of medication and information including her appointment card for Sheffield. Linda came round as the ambulance arrived and so was able to give the staff at DRI the information they needed. The duty Doctor rang Hallamshire Hospital and left a message on the answer phone as Linda had informed the staff at DRI it would be picked up next morning. Linda was kept at DRI in an observation ward.

67. Hallamshire Hospital rang the DRI before 9.00am and informed them they would be going for a review meeting and would ring back shortly. At 10:00am the Hallamshire team decided that Linda should cease treatment. The duty nurse wheeled Linda's bed to the phone where she spoke with Keiley, the specialist nurse who told her she was too ill. It was decided she should cease treatment and they would ring later that day to arrange an appointment at the Communicable Diseases Directorate on the following Monday and to talk to Linda about their next steps.
68. Linda was discharged by DRI. The following Monday she attended Hallamshire Hospital for her appointment. The blood tests they took at that meeting showed that her treatment had been successful and she was now clear of HCV. Linda was told that it would take a long period of recovery to get over the treatment. She would need a further test in six months time and if that was still clear she would be declared free of the disease. Fortunately in August she was given the all clear of HCV and was discharged.
69. Linda was kept on sick leave for a further period of time. Recovery from the treatment took a long time and it took a good year for her hair to recover
70. There have been no further medical complications or conditions as a result of HCV. Though Linda has fully recovered physically the mental scars still remain. This was evidenced when our daughter and daughter in law became pregnant and Linda found herself unable to celebrate with them until the babies were safely born. Though our daughter Faith understood, having been through the traumas with us our daughter-in law found it impossible to comprehend.
71. Following treatment Linda took early retirement resulting in a potential loss of income and an actual reduction in her pension. Also, after being diagnosed with HCV she felt unable to progress in her career as she did not at that time know whether or not she would have long to live.



72. Linda loved teaching, it was her life and love and she found it very hard to let it go. The trauma of the disease and it's treatment upon her had taken a heavy emotional toll. Linda consulted our financial advisor and her union and it was decided that with her teacher's pension, though reduced, we could manage, because you have to, until reaching state pension age at 66. Having seen the heavy emotional toll the HCV treatment had taken I agreed with her decision. Having over 30 years of Linda teaching and being home in the holidays we found it hard to adjust at first. Linda did some work for the 2011 census which helped our income. She has also done some supply teaching which has helped.
73. During her treatment Linda had to pay all her transport costs and prescription costs. Linda, as a teacher was entitled to full pay when on sick and for hospital appointments, we just paid what was necessary.

#### Section 6. Treatment/Care/Support

74. Counselling for Linda was provided by Hallamshire Hospital by Dr. Jo Nicholson. I personally received no counselling but the staff would always answer my questions. As head of the household I felt that the counselling we all received to be totally inadequate, I had to cope with Faith and Luke as well as supporting Linda with no support for me or the children. I do not blame the Department of Communicable Diseases or our GP who did their best, it was just how it was and we had to cope.
75. Counselling was never considered for Faith, Luke or myself. Linda and I feel we did our best to protect the children and answer their questions and encouraged them to talk about it freely. Faith also went with Linda a couple of times to the hospital counselling sessions with Jo. During Linda's recovery Jo queried whether Linda and Faith should attend the HCV Support group in Sheffield but the travelling was too much for Linda and there was nothing closer to home so they only went a couple of times.

## **Section 7. Financial Assistance**

76. Hallamshire Hospital put us in touch with the Skipton Fund. Linda's GP filled in the forms for her and she sent them to the Skipton Fund. Linda was granted a lump sum by them and she was told that this would be a one-off payment. Linda was aged 59 when they paid to her one year of prescription charges. Linda has also provided a statement to the Inquiry and more details regarding the application process and payments received are detailed there.
77. Linda has been inundated with mail and emails from NHS England Infected Blood Support Scheme (NHS EIBS) and this has caused more upsetting memories even though she has qualified for this financial assistance.

## **Section 8. Other Issues**

78. I confirm I have not taken part in any campaigning or litigation in relation to this matter.
79. I am not legally represented but I do have a family solicitor who is representing Linda and Faith.
80. I am pleased to have been given the opportunity of giving this statement to the Inquiry.
81. I personally am still devastated when I think that I was the one who signed the consent forms that gave permission for the blood transfusion even though I know it saved my wife's life. Thirty-six years later we still suffer from the effects of what we went through. The memories of HCV continue to haunt us to this day and every letter, telephone call or email has Linda in tears at the memory of what she has been through. This should never have happened in this so-called civilised country.

**Statement of Truth**

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

Signed GRO-C

Dated 24-01-2019