Witness Name: A Hume
Statement No: WITN1299001
Exhibits: WITN1299002-12
Dated: November 2018

# INFECTED BLOOD INQUIRY

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## FIRST WRITTEN STATEMENT OF MRS ANN HUME

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I, Ann Hume, will say as follows:-

## Section 1. Introduction

1. My name is Ann Hume and I live alone at GRO-C Scotland, GRO-C I was born on GRO-C 1952. I was married and had two children but my marriage broke down. After that I, got together with my now ex-partner and we had one child together. I left my ex-partner about twelve years ago GRO-D I am much happier living on my own. I have two lovely grandchildren, a boy aged 6 and a girl aged 9 and they are my whole world.

2. This witness statement has been prepared without the benefit of access to my full medical records.

## Section 2. How Infected

3. I never received a conclusive diagnosis regarding what was wrong with me and opinions varied from doctor to doctor. The doctors knew that there was

something wrong with me from a very early age. When I was a young girl I had a tooth extraction and I had to miss about two or three weeks of school because of the excessive and continuous bleeding. The first diagnosis I received as a child was one of hereditary haemorrhagic disorder. After that I was told that I had Haemophilia B and after my diagnosis was one of Von Willebrands Disease. However, both diagnoses were later discredited. Despite the fact that I did not suffer from Von Willebrand's disease I was diagnosed and treated for it in the past.

4. More recently I was told that I was suffering from a platelet storage pool deficiency, which is a very rare disorder meaning that I have problems with my platelet granules. My platelets cannot therefore form a plug to stop the bleeding. This new diagnosis was never fully confirmed because the hospitals in GRO-C do not have sufficiently specialist doctors or equipment to confirm the diagnosis. My haematologist, Dr Watson, advised me that I would need to travel to a hospital in Birmingham in order to have the diagnosis confirmed. I could not afford to travel to Birmingham so I applied to The Shetland Board and asked them to subsidise my travel fees. Unfortunately, they refused to do so.

5. Over the years I have received a number of treatments for my clotting difficulties. When I was young I was given snake venom on cotton wool for a tooth extraction but this did not work. I was also given 32 bags of blood plasma over a two week period in 1970 following a car accident which left me hospitalised.

6. I received Factor VIII on only two occasions, both of which were in 1982. The first was just before the induction of labour when I was pregnant with my eldest daughter and the second time was about 7 weeks after her birth.

7. What I found most shocking was that Factor VIII was given to me when my clotting level was 290%. This is a percentage found in people with no bleeding disorder.

8. I was given Factor VIII again approximately 7 weeks after I gave birth to my

daughter in 1982. I became terribly ill and I could not get out of bed. When I finally managed it I had an excruciating pain in the bottom of my womb and back. This was followed by heavy bleeding and blood clots were pouring out of me; there was blood everywhere. At the time my husband was out on a car breakdown and could not be contacted. However, the owner of the garage went and fetched him home as I was ill. Before he returned home, I was alone with my seven week old daughter and my four year old son. I telephoned my neighbour and asked for help. When she arrived she panicked and did not know what to do. She was shocked by the amount of blood. When my husband came home, my neighbour offered to look after our son and I got a taxi to The Gilbert Bain Hospital in Shetland with my 7 week old daughter and my husband.

9. The medical team at The Gilbert Bain Hospital telephoned Dr Dawson at The Aberdeen Royal Infirmary to seek advice. Dr Dawson told them to give me a bottle of Factor VIII to stop the bleeding. Shortly after that, the medical team came in with a horrifying looking bottle of Factor VIII. There was sediment at the bottom of the bottle. I actually asked why there was sediment at the bottom as it did not look right. Their response was that they did not know anything about Factor products and they were just following instructions.

10. When the Factor VIII entered my body, even more blood clots came out of me. I immediately knew that the Factor VIII was responsible for the haemorrhaging. My husband pressed the emergency bell and a number of medical staff ran to my bed. The medical team did not know what to do so they decided that I should be urgently transported, via air ambulance in a small aeroplane, to the maternity ward at The Aberdeen Royal Infirmary. My husband felt that our baby daughter was too small for him to care for her so she stayed with me.

11. I was met by Sister GRO-D who was one of the nurses, at the gates to The Aberdeen Royal Infirmary and she gave me a horrid look and angrily said *"Mrs Hume what are you doing here again! You are costing the NHS a fortune".* It was horrible and so upsetting.

12. I was diagnosed with a post-partum haemorrhage and was separated from my

baby daughter who was taken into a different unit and was left by the hospital staff to cry alone all night. I did not know about this until another patient in the hospital told me that they had heard a baby crying all night and at first I thought that this must have been one of the newborns until it suddenly dawned on me that it was my baby daughter. I was shocked that no-one from the hospital attended to her. It was so upsetting. The day after my admission I underwent a D&C operation to clean out my womb and it was not until the next day when I was finally reunited with my baby. I remember that she was handed back to me and was soaking wet from crying. We stayed in the hospital for about a week until I was discharged home.

13. I am certain that the Factor VIII, which was given to me unnecessarily, caused my haemorrhage.

14. I was never given any information about the risks of the infection. When Dr Dawson came to visit me in the maternity ward she told me that the hospital no longer used cryoprecipitate and instead now used a better medicine called Factor VIII. That was it; she provided no further information or any advice about the risks of the product.

15. I had my third baby in 1987 and was not given any blood products and I managed perfectly well.

16. In approximately 1991, when my youngest daughter was 3 years old, I began to suffer with back problems and lost the feeling in my legs. Once again I was taken to The Aberdeen Royal Infirmary although this time instead of seeing Dr. Dawson I saw Dr GRO-D, consultant neurologist. He was extremely unpleasant and rude towards me. He saw me at 5.30pm and called my name out my name from the end of the corridor and demanded that I got onto the hospital bed. He got really annoyed with me because I could not take my slippers off. At the time I used crutches to get around. He asked me why I used them and I told him that I could not really get around very well and could not take my socks off or lift my legs very high. To this day I cannot fully lift my legs. He yelled at me and went on and on until he reduced me to tears. Afterwards he patted me on the shoulder and walked away. He must have known that I was infected with Hepatitis C but he did not say anything to me

about this which I find totally unacceptable. I never saw him again.

17. Back in GRO-C, I took it upon myself to find out about The Haemophilia Society which operated in Scotland. Sometime between 1993 and 1994 I wrote to them asking to be a member. I then started to receive various correspondence and leaflets from them. One particular leaflet caught my attention. This was an educational booklet about Hepatitis C. I read through it and immediately thought "*this is me*". It was like the booklet had been written about me personally. It explained all of my symptoms and provided me with some long overdue answers to why I had been feeling so ill and exhausted.

18. I literally rushed to my doctor and asked to be tested for Hepatitis C. My own GP did the blood test and sent the sample to The Aberdeen Royal Infirmary to be tested. I received a letter from my GP, Dr. C F Mackenzie, dated 21st October 1995, which stated "*The result of your Hepatitis C blood test shows that you do have antibodies to (the) Hepatitis C virus and must therefore have had a past infection, presumably from blood products a number of years ago*". **Exhibit WITN1299002** refers.

19. I vividly remember the day the letter arrived; I was with my now ex-partner when I opened it. My partner took the letter out of my hand and said *"we cannot tell anyone about it; I will lose my job"*. I understood his fears; it was a small community and everyone knew everyone. GRO-D GRO-D

20. I was invited to see my GP at the surgery which would also incorporate some liver function tests. Following this, my GP got in touch with Dr Dawson and once again I flew to The Aberdeen Royal Infirmary.

21. GRO-C GRO-C Both mine and GRO-C's appointments were scheduled on the same day. GRO-C's appointment was scheduled for 10am GRO-D. I waited at the hospital with a friend of mine who was going to drop me off at the airport. My appointment was scheduled to take place immediately after GRO-C's but I was made to wait a long time. It got to approximately 12.30pm and I started

to get nervous because I had to catch a flight back to the GRO-C I therefore asked one of the nurses as to when my test was going to take place. She said that she would go and look for Dr Dawson.

22. Sometime after this, Dr Dawson came into the room and ordered me to *"lie down on the bed".* I was shocked and confused because she had always been so nice to me in the past. She looked inside my mouth and very briefly examined my stomach. After this examination she looked at me and said *"this never affected you at all, throw away your crutch and go and find a job".* She gave me no advice and never mentioned the words *"Hepatitis C".*

23. I left the hospital stunned and I was extremely anxious on a drive to the airport. When I got home I was in floods of tears. I did not know what to do next. I had no support and I still had very little information about Hepatitis C. The Haemophilia Society leaflet said that 80% of people with Hepatitis C would develop liver cancer. I did not know if I was going to see my children grow up. I was and am of the firm belief that Dr Dawson should have told me something and I am really upset about the way in which I was told, not too mention the way in which I was treated, and the fact that I was not given any information whatsoever.

24. My GP received a brief letter from Dr Dawson which stated that my Hepatitis C was genotype 1A and that there was nothing they could do about this. There was no information about how to manage my condition, about how I should be looking after my own health or how to prevent any potential spread of the virus.

25. Unsure of what to do, I therefore telephoned The British Liver Trust. They put me in touch with another female Hepatitis C patient, who was called Ms GRO-A.

26. I contacted her and we had a long discussion and she asked me what I was doing about my diagnosis of Hepatitis C. She asked if I was receiving any treatment and I was actually embarrassed to have to tell her that nothing was being done at all. I never heard from The Aberdeen Royal Infirmary again and when I contacted them I was told that Dr Dawson had retired and that I

was now going to be under the care of Dr Watson. However, Dr Watson had never contacted me in relation to an appointment or a check-up. When I said this to Ms GRO-A she could not believe it. She was braver than me and took it upon herself to call Dr Watson. Soon after that he telephoned me and said that he had never heard of me and did not know that I even existed. He said that he could not trace my medical records but he would look into this and he promised to contact me again once my medical records had been located.

27. Approximately three or four weeks later I received a telephone call from a secretary at The Aberdeen Royal Infirmary asking me to attend an appointment with Dr Watson. I flew to the hospital and met with Dr Watson. I was surprised by how nice he was. He told me that it was likely that I had been infected by either the batch of Factor VIII that was given to me prior to the induction of labour or the batch given to me 7 weeks following the birth of my daughter in 1982. Dr Watson also told me that I had had the Hepatitis C in my system for a long time and that I would probably go on to develop cancer as a result of it. He referred me for an endoscopy and a liver scan. Luckily the results of the scans were very positive and I was told that there were no signs of abnormal tumors or cancer.

## Section 3. Other Infections

28. **Exhibit WITN1299003** is just one example of evidence that I have been placed at risk from vCJD.

## Section 4. Consent

29. Before I started taking the Harvoni treatment I was tested for HIV without my knowledge and therefore without my consent. I was also tested for HIV about six years before that without my knowledge or consent. In 1987, I saw the advert on television with the graveyard and tombs falling down. During my next appointment at The Aberdeen Royal Infirmary I asked Dr Dawson if I

could get tested for HIV. I specifically asked for an HIV test in 1987. I recall that there was a letter from Dr Fraser at the Liver Clinic asking about my HIV status but I am unsure if any bloods were actually taken when I asked for the test. She just looked at me and said dismissively *"you will never get any viruses from Scottish blood"*.

30. It is also clear from my medical records that I underwent both HIV and Hepatitis B tests in April 1987 and both of these were without my knowledge or consent. **Exhibit WITN1299004** refers. I was tested for Hepatitis B again without my knowledge or consent in October 1987 and **Exhibit WITN1299005** refers.

31. I do think that I was used for the purposes of research. In my medical records I found a letter from The Oxford Haemophilia Centre dated 11th January 1982, attached as **Exhibit WITN1299006** which makes it abundantly clear that I was going to be a potential guinea pig. They where actively looking for people who had not been exposed to products derived from large pools and that I was one of those people. This letter even discusses research on chimpanzees. I think that they saw me as perfect research material as I was about to attend hospital to give birth to a child.

## Section 5. Impact

32. Physically I have had a lot of problems with my hands, knees, back, legs and joints. I have been and still am in constant pain and this severely restricts my mobility. I take 400 mg of Ibuprofen each day to try and ease the pain. I also use ice packs to assist my mobility. I struggle with everyday activities. I suffer from osteoarthritis, rheumatoid arthritis and fibromyalgia.

33. I was also told by my doctor that because I had had Hepatitis C in my body for so long that it has made my antibodies attack my lymph glands. I have also been advised that one of the other symptoms of the Hepatitis C are dry eyes. I have to use medicated eye drops at least six times per day. If I forget to put them in at night, I cannot open my eyes in the morning. Most mornings I have to hold a soaked cotton pad, pressed tightly, against my eyes until I can

get them to open.

34. Mentally it has been a very difficult path. The depression has been almost unbearable. My mental health problems spiraled. I started taking Dosulepin, which is a tricyclic antidepressant, to help with my depression and I still take this today. It helps with my physical ailments as well.

35. Before I was diagnosed with Hepatitis C I was completely exhausted and I never knew why. I used to try and keep going and get on with my life but the exhaustion usually got the better of me. I had no idea why I was always so tired but I knew that something was wrong. I went to see my GP on a number of occasions but he only gave me iron tablets or wanted me to see a psychiatrist as I think that he thought that my problems were all in my head. I tired distracting myself but in the back of my head I knew that I needed medical attention.

36. I found both the physical and mental symptoms very difficult to deal with on top of everything else that I was going through at the time which included trying to process the diagnosis of Hepatitis C. I had three children to look after and tried not to think about my health. Not long after my diagnosis, I told my oldest child that I was ill and that I would be getting very poorly in the future. I wanted to prepare them but this had to be balanced with not scaring them. At the time I thought that I was going to die shortly and I wanted them to prepare.

37. I had a lot of online support from the Tainted Blood Campaign Group. This was a good community to be part of particularly given that I lived in such a remote location. I do not often write or engage in any online debates but I have made one or two good friends, via the group, who are haemophiliacs. If I needed any help or assistance I could count on them. One of these friends, John McAughey was a great source of support to me but sadly he passed away recently.

38. I applied for my National Haemophilia Database records and the response I received was that they had never heard of me. Apparently Dr Dawson had never bothered to include me on the list. Furthermore, I could not get access

to my medical records. When I telephoned The Aberdeen Royal Infirmary they told me that my records were with their legal team and would not be released. It was not until I wrote to The Scottish Health Secretary that I made headway. The records were sent to her and she forwarded them to me.

39. I was in pieces when I read through them and saw the derogatory comments made by Dr Dawson. **Exhibit WITN1299007** is a letter dated 15th September 1982 from Dr Dawson to Dr Cadenhead which stated "*The situation with this girl is that we have never proved that she has Von Willebrand's Disease and it would be impossible to do this without getting her in a phase when she has had not treatment and is not pregnant*". **Exhibit WITN1299008** is another letter from Dr Dawson to Mr Johnstone at the Dental Department and is dated 1st October 1982 which stated "*This was the girl who boggled at having treatment immediately post-partum". She will need to come down 2 days early so that we can do her Factor VIII levels, hopefully in the non pregnant state*". **Exhibit WITN1299009** is a letter from Dr Dawson to my GP dated 17th January 1996 which states "*As always she is very anxious and has a fairly vivid imagination with regard to the causes of her apparent ill health. For instance she tells me that she has to walk with elbow crutches (which she was not actually using when I saw her) because she lacks reflexes in her legs. I think that she should be very strongly encouraged not to invalid herself unnecessarily with the elbow crutches and I certainly would love to see her getting rid of these altogether. I think that the evidence that she has any neurological or any other abnormality of her legs is very tiny indeed... incidentally her blood count was normal*".

40. All of the above comments were horrible and what made me even angrier was that in the past I had written to Dr Dawson and told her how much I had appreciated all that she had done for me despite the fact that she made the wrong decision when she gave me Factor VIII.

41. It is notable that Dr Dawson actually told me in 1973 that I must terminate my then pregnancy. **Exhibits WITN1299010** and **WITN1299011** refer. I did so and I have never got over this. Approximately 10 years ago I telephoned a place in GRO-C Scotland and booked an abortion healing course. This was a

residential course and it was the first time that I had properly grieved for my aborted child.

42. I cannot remember when I was first offered treatment for Hepatitis C. I think that it was about 10 years ago I went to see a liver specialist and they spoke to me about Interferon. However, I had heard that a lot of the haemophiliacs were getting really ill as a result of the treatment and I was therefore both reluctant and scared to take it.

43. I have had to undergo regular Fibro scans tests to monitor my liver. For the first six years the results were good. Unfortunately after this the results were not good and I was told that I had fibrosis.

44. In or around 2015 I read about a new treatment for Hepatitis C called Harvoni and I went straight to my GP to ask if I could try this. I was sent to see a specialist liver nurse in at The Aberdeen Royal Infirmary and she gave me the go ahead to commence the Harvoni treatment. The nurse told me to take one tablet each day and at the same time each day. She also advised that I take this at 10pm so that I could then sleep off the majority of the side effects. I felt quite sick about one hour after taking the tablet and my legs felt weak. I had to get a mediation tape as this was the only way that I could get to sleep after I had taken the tablet.

45. I cleared the Hepatitis C virus after only four weeks of treatment but I was told that I should continue to take Harvoni for another four weeks to be on the safe side. I am still clear today although I still get some pain in my liver.

46. Other than offering me the Interferon treatment, about 10 years ago, the NHS has not offered me any other treatment or support. I had to do all the research about Harvoni myself. No one came to me asking if I wanted to have this treatment. If the NHS had come to me with another offer of Interferon treatment, I think that I would have taken it. My liver was at the point that I would have had no alternative but to take it. But they did not do that; I had to come to the NHS with the research which I carried out myself and information obtained from others via The Tainted Blood Campaign Group.

47. Following the Harvoni treatment I suffered from inflammation of the scalp

accompanied by large red sores on both my scalp and face. Unfortunately antibiotics did not clear this up and I have been left with these problems ever since.

48. I believe that I have been treated differently by doctors as a direct result of my Hepatitis C. I have referred to some examples above with Dr Dawson and Dr GRO-D. Another example was after my endoscopy when Dr GRO-D advised that the endoscopy could not be repeated as the camera would need to be sterilised and therefore if I wanted another endoscopy I would have to purchase my own camera. The cameras cost about £45,000.00 and I could not afford this so I never had another endoscopy. I am aware that some people had problems accessing dental treatment but my dentist was really good.

49. My relationships and social life have been seriously affected by my diagnosis of Hepatitis C. GRO-D

GRO-D

GRO-D I found myself no longer being able to tolerate the smell of alcohol. GRO-C

GRO-C

50. My social life is non-existent. I first stopped going out socially when I became a mother caring for three children and due to the fact that I was permanently exhausted. I became very reclusive. At the time I had no idea that my exhaustion was caused by Hepatitis C. I remember being explicitly told by The Haemophilia Society in London, in or around 1995, not to tell anyone about my Hepatitis C diagnosis. Carrying a secret like this totally isolated me. I only confided in one friend. Other friends were often wondering why I stopped going out for a drink or socialising with them. Since my diagnosis I stopped drinking completely; I hated the smell of alcohol and additionally the smell made me anxious. However, I was never a big drinker; with three children you just cannot afford to drink a lot.

51. GRO-C

GRO-C Neither my ex-husband not my ex-partner got tested; they did not want to know. GRO-D GRO-D

52. In terms of earning a living, I can confirm that since being pregnant with my first child I had to stop working. I was told that I was born with one kidney, one ovary and a bi-cornuate uterus. As a result of my condition I was carrying my son on one side of the womb. This put a lot of strain on my body. My GP therefore advised me to stop working and two and a half months before my due date I was sent to The Aberdeen Royal Infirmary at around six months pregnant for fear of my son arriving early. Prior to having my children I was a shop assistant in a draper's shop and worked in an old people's home and also as a home help.

53. Financially I was reliant on my ex-husband. He gave me money for our two children. Now I am reliant on my ex-partner who still supplies me with an amount of money to keep the house going. I also receive some disability allowance money. Financially, I have struggled and I also needed to pay a cleaner to help me with the housework when my back pain was really bad.

54. What upsets me the most is that I could not do what I wanted to do with my family. One of my daughters said to me the other day *"I used to not like it sometimes when as a child we used to go to the town for a day, but now I miss it and I wish that we could do that again".* I think that having Hepatitis C stopped me from being the mother I wanted to be for my children.

## Section 6. Treatment/Care/Support:

55. I was only offered Interferon treatment once about 10 years ago. If I had been offered it again then I would have probably started it. I found out about the Harvoni treatment by chance. There was an article describing new hepatitis C treatments it in the local newspaper *"The Shetland Times"*. I contacted the author of the article directly and then approached my GP and the rheumatologist. Both of them wrote a letter on my behalf to The Aberdeen Royal Infirmary enquiring about the possibility of me undergoing the Harvoni

treatment. I had to research the Harvoni treatment myself and no one in the NHS thought to offer me this and I refer to section 5 above.

56. I remember speaking to my good friend John McAughey about my circumstances. He was a campaigner and met with doctors on regular basis. In or around 2000 or 2001 he mentioned my case to Dr Watson and said "*That lass lives in* GRO-C *which is miles away; she has no support*". When I next telephoned Dr Watson he offered me counselling. I declined this as I said that it was too late now. I had lived with both the consequences and the stigma for so long that I felt that I had learned to manage it on my own.

## Section 7. Financial Assistance

57. I found out about The Skipton Trust through Dr. Watson and about 14 years ago I received the £20,000.00 Stage 1 lump sum payment. I managed to redo my bathroom and replace the old bath with a walk in shower with hand grips. I also made some improvements to the house so that it was suitable for my condition.

58. I used to receive an annual winter fuel payment of £500.00 which I think has now increased to £1,000.00.

59. I also received £30,000.00 about two or three years ago from the Scottish Government

60. I also got in touch with The Caxton Foundation. I applied for and was successful in obtaining a grant for a new freezer .They also gave me funds for a new computer which has been a lifesaver because of how remote GRO-C GRO-C. I did have to set out that I required the computer so that I could keep in touch with people though. They paid for new reading glasses as well. In contrast, the new scheme, the Scottish Infected Blood Support Scheme does not provide grants for white goods or similar necessities. I think this is a shame because not having to worry about being able to afford such basics made the lives of those infected slightly easier.

61. I would say that the process of applying was time consuming and arduous. I had to provide voluminous records and bank statements. In fact the volume of paperwork was quite overwhelming and at first I did not know whether to bother but I did bother. Once I had jumped through all of the hoops I obtained everything that I had asked for but then again I do not think that I asked for too much particularly given how I came to be infected.

## Section 8. Other Issues

62. I was contacted by American lawyers regarding the previous litigation and I sent them my medical records but they advised that they could not assist me because I did not have the batch numbers.

63. I am not an active campaigner but I do keep up to date with the Tainted Blood Campaign Group and this has been very beneficial for my mental health and I have also made good friends via this group.

### *Conclusion*

64. I tried to make peace with what happened but it was not easy. I think that my condition was misdiagnosed and mismanaged by The Aberdeen Royal Infirmary. I do not understand why Dr Dawson gave me Factor VIII when my clotting levels were excellent.

65. I also read a book which was written in 1980 entitled "*Unresolved problems in Haemophilia*" which was edited by Dr Charles Forbes and Dr Gordon Lowe. Since this book was published in the 1980s and details the risks of contracting non-A non-B Hepatitis through blood, Dr Dawson <u>must</u> have known about those risks too. She must have given me Factor VIII with full knowledge of the risks yet decided not to impart any of that information to me and instead went ahead with giving me Factor VIII. I have no doubt that Dr Dawson knew that I would develop Hepatitis C.

66. In 2005 I made a formal complaint about the treatment I received at The Aberdeen Royal Infirmary. I received a reply dated 12th September 2005 from

the Scottish Services Ombudsman confirming "*The dangers of factor VIII concentrate as a source of non-A non-B hepatitis, later identified as hepatitis-C were known at the time.......Dr Dawson was in the forefront of medical research in this field in the 1970s/80s*". A copy of this letter is attached as **Exhibit WITN1299012**.

67. I have no respect for Dr Dawson. She ruined my life when she gave me Factor VIII when I did not require it.

68. I also read that Factor VIII should only be used in life or death situations or for severally affected haemophiliacs. I was in neither situation; I just wanted to have my baby. Factor VIII was a potentially dangerous product and should never have been used as a preventative against bleeding in childbirth. I am certain that it caused the haemorrhage by over clotting my blood.

## Anonymity, disclosure and redaction

69. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I will be unable to give oral evidence at the Inquiry due to my health problems including lack of mobility.

## Statement of Truth

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

Signed GRO-C

Dated 30 - 11 - 2018.