

ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN0610001

Exhibits: WITN0610002-9

Dated: 2/4/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 9 November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1944 and my address is known to the Inquiry. Present when my statement was taken were my wife, GRO-B and my daughter, GRO-B. Their dates of birth and addresses are also known to the Inquiry.
2. I am married, with two children. After 12 years in the GRO-B I became a ship's pilot abroad. From 1978 to 2006 I was a GRO-B. I am now retired. I intend to speak about my son, GRO-B: S who was infected with HCV via transfusions he received during his treatment for Acute Lymphoblastic Leukaemia. In particular, I will speak about the nature of his illness, how the illness affected him, the treatment received and the impact it had on him, my family and our lives together.

Section 2. How Affected

3. On 2 January 1990, at age 3, [S] was diagnosed with Leukaemia. We were blown away. To be told your child has leukaemia. They rushed him off to Queen Elizabeth Hospital (QEH) that night for chemotherapy. After about 3 or 4 weeks we came back to QEH and then Great Ormond Street Hospital (GOSH) offered a bone marrow transplant. [S] was a perfect match with his sister, [GRO-B]. We were very lucky because it was a one in four chance. [GRO-B] was a perfect match, a perfect skin type. It was like they were twins.
4. Between January and March 1990 we were in Queen Elizabeth, which was in those days allied to GOSH. We went in to GOSH at the end of March and on 4 April 1990 he started the bone marrow transplant.
5. [S] was sealed in an airtight unit at GOSH. They only had 6 cubicles and they only took people with the best chance in. [GRO-B] was with him all of the time. There were a lot of complications and he nearly died on one or two occasions. At one time he had 22 drips going in to him, possibly more, because once he had started a course of antibiotics he had to finish it. It was like a spaghetti junction and the last bit was a Hickman Line, because he could not do injections or needles at that age. I was in the cubicle with him one day when he had all of these tubes and various things. The alarm went because there was a leak on one of them and I had to try and trace this leak before the bubbles went into his heart. The doctors could not get in quickly enough to help. I literally found it just in time and pressed this little button on the tube. It was difficult trying to tell [S] that he could not go home. 3 months in that thing was hell for him.

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6. [S] eventually got through it. He did very well. We had got to know six children like [S] in the hospital, and only [S] we know is still alive. In some respects I wish that he had not got through it because he has suffered more now in later life.
7. [S] had about 80 transfusions of blood products ongoing through that period. Some were red blood cells, white blood cells, platelets, plasma. I am not sure which might have infected him, but he was about 3.5 to 4 years old when he was infected. I do not know if he ever really had a lot of whole blood. I think it was mainly just blood products. The doctors did not tell us of a likelihood of any infection.
8. They did not do any tests until [S] was about 14 or 15 years old so we found out about [S]'s HCV infection roughly 9 years and 9 months later. It would have been late 1999 or early 2000. We got a letter from GOSH who told us they had been doing a survey and wanted to know from their own records how many children they had infected. They were a wealthy hospital so they could afford to do it. A lot of hospitals could not. They thought it would be 3 to 4%, but it turned out to be 5 to 6%. One of those children was [S].

Section 3. Other Infections

9. I do not believe that [S] received any infection other than HCV as a result of being given infected blood products.

Section 4. Consent

10. We knew that [S] was receiving the platelets and plasma, but the doctors did not say where it was coming from.

Section 5. Impact

11. About a year to 18 months after being told, [S] started treatment with Interferon and Ribavirin. When you are 16 years old, you should be transferred from GOSH to another hospital. However, because of the HCV infection and long-term Leukaemia follow-ups, GOSH kept [S] on. GOSH did not want to do any treatment, they said he had a mild infection and to leave it and see what happened.
12. GOSH kept him on until he was 18 and then had to transfer him to the University College London Hospital (UCLH). Almost immediately the doctor there decided that [S] had a medium infection and that we should do something about getting rid of it. [GRO-D]
[GRO-D]
This is when they put him on the first course of Interferon and Ribavirin.
13. Before his first dose of Interferon, [S] hardly ever got ill. He was a happy little chap. The Interferon was a killer. [S] did have Brittle Bone Syndrome after his chemotherapy, but that was it. There was nothing else before the Interferon. I wish we had never done it now. Looking back, [S] would have like to have stayed with the Hepatitis C infection. However, we thought we were lucky because we were offered it so we took it up.
14. The doctors explained that there are side effects some times. The main thing they said was that his personality could change and that he would be impotent because of it. [S] is sterile forever now. That is a difficult one because he now does not have children. If it had not been that [S] had taken Interferon, he would not have had this breakdown. He did not have any mental health issues, absolutely nothing, before. Before the Interferon he was a happy child.

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15. I had always injected [S] [S] is very short. He is 5ft 1. The doctors could measure how tall they thought he was going to be and they thought 5ft 10. GOSH put him on a growth hormone for his confidence to build him up a bit. Unfortunately, he was almost at the end of his bone growth, but if they had done it earlier he might have been 5ft 5 to 5ft 6. He was always normally about 9 ½ to 10 stone. Now he is 5 stone.
16. But when [S] was transferred from GOSH to the big hospital at UCLH, [S] made the decision to inject himself. This would have been about 2004 to 2006. They told him to inject himself in the stomach. He was a chubby little chap then and when he injected he would lean forward to see so that of anything he put in, half of it would come out. For the first 6 months any treatment did not work. I wish he had let me do it because then we might not have had these problems. There were no major side effects after the first course.
17. We were told the treatment had not worked and we thought that was it. At GOSH he had had liver biopsies but it was done slowly and under anaesthetic, there was no discomfort. At UCLH he was considered an adult and it was done there and then. [GRO-D]

[GRO-D]

[GRO-D]

[GRO-D]

[GRO-D]

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18. That liver biopsy was after the first course of Interferon and Ribavirin. The infection was still detectable and we did not know at that time if they would offer a second appointment. [S] then got thyroid cancer and we had to wait to get that back to normal for another year. I do not think the thyroid problem was linked to the HCV infection. I think that was because of the cancer he had when he was younger.
19. [S] then went for a second course of treatment for the HCV around 2008 and was taking these horrible drugs for about a year, then a half a year of waiting. For this a second course of Interferon and Ribavirin, both together again, but they tried a different manufacturer this time. [S] completed the full course the second time and it expelled the virus but left the residual damage to the brain. As far as we know it is still expelled. [S] is scarred mentally I think.
20. After the second course [S] suffered from depression and terrific anger. It made him feel so ill. [GRO-B] remembers one incident where [S] was raging and he came at her with a broom handle and tried to push it through her. He pushed her against the stairs and bruised all her ribs. He has also pushed [GRO-B] against a wall out of extreme rage. When he was threatening [GRO-B] I stepped in. He never had a temper before, the treatment was responsible.
21. [S] has also tried to push me out of the front door and on that occasion I went to hospital because I had a feeling in my chest. He has also said that he knows where there is a machete and that he knows how to use it. So knives, scissors – we hide them all. [GRO-B] is terrified of leaving [S] and I together because he was particularly volatile toward me. [S] has not come into our home for about 4 months now. The anger is still there.
22. We get the impression because he was one of the few kids that had gone through puberty, adolescence and adulthood, that he was

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always a test bed. Hospitals monitored him from the beginning. He was used like a guinea pig. I get that impression. He was never the same after the damage. He never did feel good. His condition went from bad to worse.

23. Soon after the second treatment, about a year or 15 months after it was finished, someone had pointed out that there was a swelling in his neck. We went back up to UCLH to see the consultant. They decided he had a tumour in his parathyroid glands. There are four little glands tucked in the neck which control calcium levels. Apparently they took two lobes off. They were tumours and they were benign, but they might have developed. GRO-D

GRO-D

24.

GRO-D

25. In December, for one reason or another, we did not have enough calcium and he collapsed again. Since then he has not had any more operations but the mental illness was there, the scarring of what has been done.

26. S does not live at home because there is so much anger between him, my wife and I. It is so peaceful at home when it is just GRO-B and I. S lives in a little flat. He is unhappy with it, desperately depressed and has paranoia. It is quite social in town with people who understand him, but S does not get on with many

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people from the outside world. There is a lot of jealousy and anger because he hears people having drinks, going home to husbands and wives. We had to buy his place on equity released from our home. So that is where the extra money would have helped, but he just missed out. If we would have got that [S] could have a nice little semi by now, perhaps a dog even.

27. Instead it just gets worse and worse. Mental health, police, threatened, robbed with knives, robbed with broken bottles. [S] was taken off to the bank at 4am in the morning one time. The police have seen him being robbed but when [S] reports it they say they cannot do anything because they did not hear what was said. I was astounded but there have been too many incidents like that. [S] calls the police in the middle of the night sometimes and we have had the police here lots of times. The police are doing lots of work for mental health care. The police have been very good really on the caring side if not the crime side whole, but we do not want to have to have them round.

28. What we are fighting for with the doctors at the moment is a government controlled tablet because [S] is suicidal. [S] will take sleeping pills and on several occasions [GRO-B] has run him to the hospital by ambulance. [GRO-D]

[GRO-D]

[GRO-D]

[GRO-D]

[GRO-D]

[GRO-D]

There is a medical document from GOSH, dated 2003, which shows a thorough medical examination, and there is no mention of mental health issues there. That is because there were no mental health issues before the Interferon.

[S] was a different person before he went on that.

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29. GRO-B does not want him back here and he does not want to come back. It is not that he does not like us, it is just that he remembers the pain. The bedroom he grew up in he does not want to live in again.
30. Between one thing and another I do not know where to turn. S asks for our advice but he never listens. If there is something I am not sure of or I do not know, I will listen. I will not argue. But S always has his own opinions and we quite quickly breakdown and start arguing. I go quiet. We have got Christmas coming again. We are going to my daughter's but without S. The question is what to do with S because one grandchild is 3 years and the other one is only 5, and he has scared both of them before.
31. GRO-B is taking tablets to help her calm down. She spends 7 to 8 hours every day on phone to S. Generally he phones us and now she has had to cut the phone off after 9pm. Within an evening he might be on the phone for 3 hours. He just goes on and on and on. He did sometimes call at 2am and tends to go on about the same things. We just have to put the phone down, or switch it off.
32. This has affected everyone. I have quite extensive psoriasis, as does S GRO-B and I are now on blood pressure tablets, I do not take anti-depressants, but she does.
33. My daughter has no eyebrows. She picked her eyelashes out when she was 13 because of the stress. She had years of not having them because she kept doing it. She loves her brother but he is difficult to live with. She got them back in time for her wedding. However, S became quite intense again and she begun pulling out her eyelashes again. GRO-B remembers coming in 2 years ago. We wanted her to check on S when he was staying here. She felt on edge and was scared of him. She said she felt like she needed to remove herself because he was unpredictable. GRO-B has started having counselling, but her main thing was her anxiety and her lashes.

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34. When [S] was in GOSH, [GRO-B] stayed with him there for the 4 months. My mother had just become a widow so she came to [GRO-B] to look after [GRO-B]. At that time I worked 24 hours on and 72 hours off. So I worked 1 day, visited GOSH the next and spent the third either at GOSH again or would do the shopping etcetera and spend some time with [GRO-B]. As an indication of how she was affected by this at age 7, she asked [GRO-B] only late last year why she never came home to see her. A look at the hospital photos, and an explanation soothed her. But she felt this after nearly 30 years!
35. We have had [S] here with her kids and he shouts. The poor little 5 year old has been beside himself, knocking to try and get out the door. There was once a big row and her son would not go near his other grandparents. He has shown massive signs of aggression at school. [GRO-B] shouted at [S] once and her son was affected by that big time. [GRO-B] does not want the kids here when [S] is here anymore.
36. [GRO-B] weakest point is her mental state. She is on the edge and takes 6 antidepressants a day to keep her level. She drinks up to a bottle of wine a day as well. She also gets a dry mouth and has to drink a lot of water, and she also has asthma. I have not smoked for 10 years and have not been drinking much either. [GRO-B] thinks that is amazing. Her blood pressure has gone up and is on treatment for this, which she was not on before [S] infection. If she gets into a rage it upsets me because she is not really like that. She is very defensive of [S] she is very protective and she always forgives him. When the grandchildren are around her blood pressure goes right down and she calms down.
37. [S] never had depression before the Interferon treatment. During the treatment that made you feel very ill, he was constantly told you

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will feel great 3 weeks or so after it. He expelled the Hepatitis C but the dark feelings remained and then the depression started.

38. The depression progressed into extreme anxiety and depersonalisation. [S] has always wanted to cuddle his nephew and niece but never does because they feel like ghosts to him. He feels as though he can put his hand through a wall. It is called depersonalisation. This is why we are trying to get him help because when he has his benzodiazepine tablets it goes away. But it is just these tablets that the Government wants restricted and therefore many GPs will not prescribe enough of them.
39. [S] has light sensitivity with his cataracts, which developed as a result of the original radiation. The Interferon made these cataracts worse. It makes him light sensitive to the extent that he has worn 3 or 4 pairs of sunglasses at the same time. He has a plastic screen on the TV because he cannot look at a light on the TV. When he was staying here he switched off everything, every little light. He even stuck blue-tac on all the little lights to cover them up (e.g. when the TV is on stand-by). At Christmas he wanted the tree lights off. At his flat one time he had thick black curtains and took all the lightbulbs out. But when he has his benzodiazepines he can go off to the pictures.
40. [S] plays guitar quite well and has written a few songs. He played for us and made us watch his 'concert' at home, which is a new thing for him. I felt embarrassed and sorry for him. All of that has been since the second treatment of Interferon and Ribavirin. No matter what the doctors say there was no depression whatsoever before this. He did not have any anger. He was not an angry child.
41. [GRO-B] knows that her parents are getting older and is this all going to land on top of her lap when we pass. She tells her mum that she has got to be cruel to be kind, because [GRO-B] cannot do what we do for [S]. [GRO-B] gets a lot of panicked phone calls from her

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mum. It has been a strain on her marriage. [GRO-B] does not stand up to [S] as much as she should.

42. [S] often acts on things without thinking it through. He often goes straight to [GRO-B] husband, who has his own physical problems. Before their marriage in [GRO-B], [GRO-B] s now husband broke up with her because the stress of the family was too much. She was terrified of leaving [S] and myself alone and so she was spending a lot of time here at home, but now having their own kids' things are more settled.

43. We had to have [S] removed from our house by the police a couple of times. When asked by the ambulance service if he was violent, [GRO-B] said that once he came at her with a knife. Ever since, if paramedics are called, the police come too.

44. I bought [S] his own premises in August 2016. This has given us a bit of relief at home but it has caused more problems for him in the town. I bought the flat so that when [S] was ready the flat was there. Against my better judgment and under pressure from [GRO-B] and [GRO-B] I got rid of a good sitting tenant and installed [S] in his place. We put [S] in the flat and he has treated it as a doss house. It is in a terrible state. When we put him in the flat we put everything in it; bed, TV, tables, a broadband package. He moved in and got rid of it all. He put the blackout curtains on. He has not made it a home. He does not have a bed and he sleeps on the floor. But when he stays in a hotel he does sleep in a bed.

45. It wears us all down. I have done most of the letter writing and [GRO-B] does the medicines and the care. Everything we do revolves around [S]. If he is doing well we might go away. But we might plan a trip and then we suddenly discover he needs something. It makes [GRO-B] feel guilty to go away and so often she does not go. There are some trips where we have had to come back early. I go away to my [GRO-B] in

Holland as a refuge. The longest I have been gone is about 6 or 7 weeks [GRO-B] would like to be there too but she has to stay.

46. One of the worst things to happen to [S] is when we found out about the parathyroid gland. He had done about 3 years of an access course to go to university. He was either going to go to [GRO-B] ([GRO-B]) or [GRO-B] in the [GRO-B] Hospital there. He was looking forward to it. For 3 months he employed a tutor to help with maths. He was depressed then but not that bad, and this was well after the course of the second treatment. Then he went in for this and the doctors said it was urgent and had to be operated on then. They would not wait. We asked if it could wait 3 months so he could finish the course but they would not because it could be malignant. It was after that operation that we had calcium problems and we almost killed him twice. He wishes he never had that operation. The university offered to hold his position open for a while but he was never well enough to go back to school or university. He wanted to study moving pictures and CGI.
47. Following his Leukaemia and Hepatitis C treatment, we have travelled from London by car and train – it has cost us thousands, we had no compensation at all. It all costs and we got nothing. And I cannot help him further now with his house because of it. This hurts [S]. He would like a family and kids. He sees everyone else doing well. He was a loving and generous person whose life has been changed. I really think it would have been better if [S] had slipped away when he was three.

Section 6. Treatment/Care/Support

48. We still have a lot of help from GOSH or UCLH. I cannot really fault anything they have done other than they gave him this stuff in the first place, which was not their fault. The local hospital has recently been in the news for its problems, but the physical treatment there has

been good and the follow-up very good. GRO-D
GRO-D

49. The mental health treatment in this area has been awful. We are happy with physical treatment but mental health support has been appalling, just diabolical. And now we cannot get the benzodiazepine. S is on 4 benzodiazepine. We want 6 or 8. The doctor took him off 10 benzodiazepines all in one go. That could have killed him. GRO-B is waiting to speak to a doctor who is a specialist. We are having to buy medication because we are not getting the support that we need. Government Health Department Policy is for a maximum of 4 a day, many but not all GPs follow it. The UCLH doctors say S needs more and always will, but they do not issue prescriptions. Only GPs can, and unfortunately most of the foreign doctors we see do not use any initiative and just follow the guidelines. We are aware that some people could have 20 a day, but S has only been prescribed 4. The ones we are having to buy on the internet are apparently not working and not having any effect. They are a well-known make but they are different to the ones S is used to taking.
50. Because S lives in town, he has used several of these foreign doctors in such practices. We have tried 3 different surgeries in town for S and cannot get through past their secretaries. GRO-B lost her temper, they have got nasty and put the phone down. One doctor has dumped him because of GRO-B anger. I have recently written to the General Medical Council to put pressure on medical doctors to get S the treatment he should have had, but they will not do it. They do not use their initiative. The GMC will do nothing to help us.
51. S has had similar problems with the local mental health doctors; usually they are Pakistani. At first in 2008 – 2009 we had decent doctors here, but they move on, less helpful foreigners have replaced them. S has had no continuity with these psychologists through

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no fault of his own. Funds for the medical services have drastically been cut and time between appointments increased.

52. They called in coordinators to help manage relationships between psychiatrist and patient. [S] had a couple of coordinators who were downright cruel. They would promise to meet for coffee and then they left him sobbing on high street and walked away when they had had enough. A member of the public found him and phoned us. Another psychiatrist saw him crawling out the door at Christmas - they watched him go and said 'Happy Christmas.' The local mental health service is worse than bad, it is diabolical.
53. I wrote a letter to the Chief Executive of [GRO-B] Mental Health Authority and then things started to move. We got to the situation 3 or 4 years ago where [S] was top of the list. It was semi secure, this place called [GRO-B] It had a garden. We were just waiting for a place in this institute. That would have followed up with the council/housing association giving him a little flat or cottage. [S] did not like the attitude of this psychiatrist, Dr [GRO-B]. He was useless to [S] and at times quite cruel. So in anger of one meeting [S] came home and wrote a letter stating he had had enough with their whole outfit and was leaving. Not realising (not talking to me for advice either) that he would be throwing all this help and accommodation we had worked for. He has done this several times, undoing all the good I and others have been trying to do. We were offered family counselling, 2 sessions to tick a few boxes, the meetings secured nothing. A waste of time for us but I expect it was good for the records!!
54. [S] has been admitted to a mental institution on a number of occasions. The first time was for about 11 or 12 days. He stayed in but did not like it. He wanted out and they agreed with him. The next two times the police took him in. He was examined by two doctors the next day and they sent him home. In fact one of them, the second

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time, found out that [S] had got money from the Skipton fund and told him to go off and have a holiday. The psychiatrist advised him to spend it all.

55. About a week or 10 days ago he called 111, and he sounded so distressed on the phone that the lady did not just make an appointment, she sent an ambulance. The ambulance people came in and were astounded that [S] did not have a coordinator. They took it on themselves to try and get him meals on wheels, a health visitor, and said that they would let his doctor know he's not well. It has not happened. We should have a social worker, nothing became of this either, as we have to go through the aforementioned GP.
56. We have tried to access mental health help and get a social worker, but we get nothing. [S] just wanted someone to visit him twice a week, to get him his drugs and sort his meals. Nothing happened as usual. Other experts, doctors, police, paramedics, the council, are amazed [S] does not have a dedicated social worker.

Section 7. Financial Assistance

57. I do not recall how we found out about the Skipton fund, but we filled in the forms out and got £20,000 from Skipton, which was the standard. We got that probably around 18 months to two years from approaching them.
58. At first we just got that. Recently they started giving [S] about £150 a month. I always used to watch his bank accounts so that I could transfer money in if he was short. He got this idea that I was taking money out so he keeps changing his password and now I have no idea what he has got in the bank. I have never taken money out. I think he receives about £259 from Skipton now. But the problem is that it has all changed and it has gone into one unit so now I do not

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know and [S] will not tell me. I have not seen any letters, but I think it was something like £259 the last I heard.

59. I probably did the paperwork and asked him to sign it. I am his appointee for some of his benefits because he was wasting so much. Some of [S]'s benefits go into his account and a couple go into mine. The ones that go into mine pays for the flat and maintenance and things like that.
60. I do not think I had to sign anything that waived future claims [S]'s payments now come from the Paxton foundation and later also the NHS Services Department.

Section 8. Other Issues

61. Somebody at Great Ormond Street Hospital was on to this class action that was going through the courts. The nurse in the follow up clinic must have been aware and she told us. We did not know about Skipton at this stage. A solicitor in [GRO-B] took us on. He was very good and we have been in contact with him since. He took us on but could not get [S]'s details ready in time for us to go on the class action. It was about 20 or 30 children. I am not sure exactly how many, but it was successful. The Court put a 10 year stop on claims, from the date of infection, and we did not get ours in on time. We missed it by about 2 weeks or 10 days. The whole thing was ready to go to court otherwise.
62. Our solicitor thought that was very wrong so tried to take [S]'s case to Europe. It got quite a long way and had to go to a barrister who specialised in European Law. We had legal aid right the way up until this point, but because we were on legal aid the cost of bringing the case was so high compared to the possible rewards that they had to drop it. I could not attempt it myself so we just went through life. That would have been in about [GRO-B] to [GRO-B] A little girl with an

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almost identical infection to [S] and of a similar age got £160,000 in compensation. [S] got nothing. About this time we found out about the Skipton Fund.

63. The following exhibits were presented to the investigators who took photographs of them:

Exhibit number	Contents
WITN0610002	Typed list of medical conditions. [GRO-B] Medical Practice ends 23 Jul 2013
WITN0610003	Handwritten list of medical conditions appears to carry on from WITN0610002
WITN0610004	UCH letter re [S] diagnosis dated 31.1.08 (Page 1 of 2)
WITN0610005	UCH letter re [S] diagnosis dated 31.1.08 (Page 2 of 2)
WITN0610006	UCH letter re [S] titled Hepatology dated 28.2.08
WITN0610007	UCL Pharmacy form dated 31.1.08
WITN0610008	GOSH letter to GP dated 11.11.03 (page 1 of 2)
WITN0610009	GOSH letter to GP dated 11.11.03 (page 2 of 2)

Statement of Truth

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

Signed

[GRO-C]

Dated

2/4/2019