Witness Name: GRO-B

Statement No.: WITN0265001 Dated: 6-5-2019

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 15 February 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

- 1. My name is **GRO-B** My date of birth is **GRO-B** 1959 and my address is known to the Inquiry. I am a third generation cattle and sheep farmer on a family run farm. I have worked on the family farm for most of my life, since around 1987. I now live and work on the farm on my own, my mother and father have both passed away.
- Prior to working on the farm, I worked for about three years as a mechanic in <u>GRO-B</u> GRO-B and I am the fourth eldest.
- 3. I intend to speak about my infection with HIV and Hepatitis C through contaminated blood; the death of two of my brothers who were also infected with HIV and Hepatitis C through contaminated blood; and the

infection of my other two brothers with Hepatitis C through contaminated blood. In particular, I intend to speak about the nature of our illnesses, how the illnesses affected us, the treatment received and the impact it had on our lives.

Section 2. How Infected

- 4. I was born with severe haemophilia A. Four of my brothers are also haemophiliacs, but my youngest brother is not. My father did not have haemophilia, however my mother was a carrier. Two of my sisters are also carriers, and one of them has a son who also has haemophilia.
- 5. I was first diagnosed with haemophilia in approximately 1960 when my first teeth started to come through and I bit my tongue. It would not stop bleeding so my mother took me to the hospital because she knew that something was wrong. The doctors were not sure what was wrong with me and it took them a long time to figure it out. A few years later, in around 1962, I got a medical card confirming that I had haemophilia from the Royal Victoria Hospital Children's Ward.
- 6. Bleeds into the joints are the worst because the pain is brutal I cannot explain how painful it is. I have had teeth pulled out without anaesthetic, and even that is no comparison to the pain of a joint bleed. On a scale of one to ten, having a tooth pulled is a one while the pain of a bleed into a joint is a 10. The bleed can happen at any time if you get a knock, or even spontaneously at night for no reason.
- 7. Factor VIII was not a treatment for haemophilia until I was about 10 years old. Before this, when I was younger, the doctors would experiment with various things in hospital to alleviate the pain from a bleed, but they didn't really know how to solve the problem and how to treat it. For example, they would put my knee in plaster of Paris, but

because I was young and in so much pain I couldn't sit still and would sometimes fall off the bed. My knee would hit the floor and the pain and the bleeding would get worse. I remember the doctors putting needles into my swollen knee at times because they thought that there was fluid in it, but it was actually swollen muscle. At that time they just didn't have any treatment that could help.

- 8. When I was about 10 years old the doctors realised that Factor VIII was a good treatment. I would go into the hospital and get the Factor VIII administered through a drip. I don't remember any risks of Factor VIII being communicated to me, but I was very young so the doctors may have discussed this with my parents – I don't know for sure.
- 9. By the time I was around 15-16 years old, the doctors supplied Factor VIII in frozen form so that we could administer it ourselves at home. We kept it in the fridge, and my four brothers and I all used the same batch of Factor VIII whenever we had a bleed.
- 10.1 used Factor VIII regularly more or less every time I took a bump. I needed to use Factor VIII more often when I was younger, because when you administer the Factor VIII you are meant to sit and rest to let the bleed heal. As a child I was always running around and did not always do this, so the Factor VIII didn't always take effect. This meant that sometimes I needed to take Factor VIII more often.
- 11. Having haemophilia also means that when I cut myself or have a bleed I lose a lot of blood. I have sporadically received pints of whole blood over the years, for example, when I had a stomach ulcer or when I lost a tooth. I received pints of blood throughout my childhood and up until about 12-14 years ago.

Diagnosis with HIV

- 12. In 1985, I received a letter from my main doctor at the Royal Victoria Hospital – Dr Elizabeth Mayne. In the letter she said that she had noticed something unusual in my blood test results for the past two years, but had been unsure of what it was. However she said that she now thought I had HIV. This was the first time she actually told me about it. I went to see her face to face, and again she explained that she had suspected that there was something wrong with my blood tests since about 1983, but this was the first time she felt sure that it was HIV. She had noticed the same irregularities in the blood test results of two of my brothers as well.
- 13. The doctors did not know exactly when I contracted HIV, and were not able to pinpoint the exact batch of Factor VIII that caused the infection. However, based on Dr Mayne noticing something amiss in my blood results for two years prior to 1985, they think that it is likely I was infected sometime in 1983.
- 14. Dr Mayne specifically told me that contaminated blood was the cause of my infection with HIV. She said that the blood used to make the Factor VIII treatment that my brothers and I had been using had been contaminated with the HIV virus. She seemed positive and was in no doubt that this was how I contracted the virus.
- 15. At the time, I had never heard about AIDS or HIV before and did not know anything about it. Dr Mayne explained what the virus did to the immune system. She said that while I was currently fit and healthy, I could be very ill in a few years, and catching a cold or the flu could kill me because my immune system may not be able to cope with these things in the future. She told me that if I took care of my health, ate well and didn't drink or smoke, I might live for another two years. When those two years passed and I was still alive she extended this time

frame and said that I had maybe another 5 years, then another 6 years to live. She really didn't know how the illness would progress.

- 16. When I was told that I had the HIV virus in 1985, Dr Mayne did lots of tests on me. She took blood straight away on the day she told me, and there were further tests every six weeks to keep an eye on the way the virus was evolving and to monitor my health. There was no medication at this time, but every time they did a blood test Dr Mayne would call me and say that I was as healthy as a cow.
- 17. Dr Mayne explained everything to me really well and she was very genuine. I think that she explained things to me the best she could at the time, but the virus was relatively new so she didn't know everything about the virus or all of the ins and outs of how it progressed. However she was constantly finding information out from other countries and hospitals and I don't think that she hid anything from me. We had a good relationship and she was a good doctor who was trying to pick up information about the illness from the television and through her colleagues and medical sources. However she was very clear on how I had been infected with HIV - she knew it was through the Factor VIII I had been receiving. She specifically used the term 'contaminated blood' and was very honest about it. Over time, Dr Mayne seemed to really get to grips with understanding how the HIV was working and how the virus turned into AIDS. She was studying it and reading about it, and was trying to learn as much as she possibly could so that she could update me and tell me how it was affecting me. She really did make the best effort to keep me informed and updated.
- 18. When she first told me that I had HIV in 1985, Dr Mayne explained how the virus could be spread to others. She said it could spread through cuts, through brushing my teeth and that I should never let people use my toothbrush. She said I should never share needles, and that I

needed to be careful during sex. She explained everything fairly well at that early stage.

- 19.1 continued to take Factor VIII after I found out about my HIV infection because of the indescribable pain of a joint bleed; there was no such thing as sleep when I had a joint bleed. I was in pain and had no other option but to continue to take the Factor VIII. Even though you can take morphine for the pain now, you still need to take the Factor VIII to stop the bleeding first because otherwise the morphine will not get rid of the pain completely.
- 20. Sometime in the 90s, maybe the mid-90s, I remember being told that the Factor VIII was now being heat-treated and that I would not be able to get anything from the blood anymore. Since around 2000 I have been using manufactured Factor VIII instead of the kind made from human blood – I think it is called Recombinant Factor VIII.

Diagnosis with Hepatitis C

- I was diagnosed with Hepatitis C probably around 2003, but I cannot recall an exact date. I am not completely sure because I was not particularly worried about it at the time.
- 22. By this time the Haematology Unit at the Royal Victoria Hospital had moved to Belfast City Hospital, and Dr Mayne was no longer treating me as she had retired. Dr Anderson was my new doctor for a short time, and was the person who told me that I had Hepatitis C.
- 23. When Dr Anderson told me that I had Hepatitis C, all I can really remember is that I was told the Hepatitis C would affect my liver and was similar to drinking too much alcohol. Dr Anderson told me how Hepatitis C could be spread, and said similar things to what Dr Mayne

had when she told me about the risks of HIV: that it could be spread through cuts, rag nails, sex, drug use, and that it could even be spread if the cuticles around my nails were bleeding and came into contact with someone else.

- 24. Dr Anderson said that I contracted Hepatitis C from either Factor VIII, or possibly from a pint of contaminated blood from the many blood transfusions I received. They were not exactly sure when I had been infected and did not put a definite date on it. However based on the information from Dr Mayne and her suspicions about my blood tests in the two years prior to my HIV diagnosis in 1985, they said that it was likely to have occurred around the early 1980s.
- 25. There was no treatment offered for Hepatitis C when I was first diagnosed. Dr Anderson said that I had to be careful not to abuse my liver and that I should not drink because this could allow the Hepatitis C to cause more damage. However, there was not much information. I don't think that was the doctor's fault because a lot of the time I didn't want to know the details I just wanted the information quickly so that I could leave.
- 26. Dr Anderson is gone now, and Dr Benson is currently my doctor at the Northern Ireland Haemophilia Comprehensive Bridgewater Suite at Belfast City Hospital. This is where I get all of my blood tests done now, including testing for cholesterol, diabetes, HIV and Hepatitis C.

Section 3. Other Infections

27. While the doctors never confirmed that I had Variant Creutzfeldt-Jakob disease (vCJD), after the BSE ('mad cow disease') scare in the mid-90s, whenever the doctors sent me a letter they would mention HIV, Hepatitis C, and say 'possible infection with vCJD'. They explained

to me that vCJD could be transmitted through blood, and although they never said that I actually had it, all correspondence from my doctors would mention the possibility of vCJD. I should have checked more about vCJD but I had enough going on with HIV and Hepatitis C, and I didn't want to know anymore - I just blanked out the possibility of asking more about vCJD and whether I actually had it.

28. Aside from HIV, Hepatitis C and the mention of vCJD, I am not aware that I have been infected with any other viruses through my treatment with blood and blood products. I have blood tests done all the time. Initially after my diagnosis of HIV in 1985 I had tests every two weeks, but over the years the number of blood tests has reduced. Currently I get tested every six months for Hepatitis C, HIV, diabetes and other things.

Section 4. Consent

- 29. I was never asked to sign anything or give consent in relation to Factor VIII. I'm not sure if or how my parents provided consent for me to receive Factor VIII as a child. The only time I had to sign anything was when I had a knee operation.
- 30.1 also gave signed consent for the Hepatitis C treatment I received.
- 31. I never signed anything for the HIV medication I took in the past, and I have not signed anything for my current HIV treatment. It is just an ongoing thing.
- 32. I don't think that I was experimented on or used for research, although the thought did cross my mind because I was given so many different types of HIV medication and it was always changing. Whenever I had a new medication they would do lots of blood tests, so for a split second I

would wonder if the blood test was to make sure the medication was doing what it should be and helping me, or whether they were experimenting and had no real idea what was happening. However these thoughts only lasted for a split second and I generally don't feel like I was experimented on.

Section 5. Impact

- 33. When I was told about my infection with HIV through contaminated blood, I felt sick and rotten. After I was told, it felt like all of a sudden AIDS was all over the news and on TV. Everywhere I looked there was news about HIV and the AIDS epidemic so it was impossible to get it off my mind. I just felt really rotten and couldn't stop thinking about it.
- 34. Dr Mayne had initially said that I might only have 2 years to live, so I didn't cope well when I was first diagnosed with HIV. I just kept thinking 'Why me? Why did I have to be a haemophiliac?' A lot of thoughts went through my head. However, later down the line I tried to stop thinking about it too much and I would distract myself by keeping busy with the farm and dealing with the cattle. When I keep my mind occupied I can get through most of the day without thinking about it.
- 35.1 never blamed the doctors because they were just doing their jobs. However, the fact that the contaminated blood was coming from America annoyed me more than anything, because it was bought from prisons. I had heard that the president had a private business and was buying blood from prisons and selling it to the NHS to make a profit. I learned this information from the media, and the doctors did say that blood was coming in from other countries and from America in the early 1980s.

- 36. At first, because all my blood tests came back clear and healthy, I never took any medication for HIV. The first time I took medication for HIV was in 2003 when one of my ankles swelled up while I was walking my cattle. I thought it was a bleed and went to the hospital. When I was in the hospital they said that the swelling was a result of the HIV and that the virus was getting more serious. I was in hospital for 7 weeks. Food would not stay down and I was constantly sick. They wanted me to tell my mother and father that I wasn't coming out of hospital, but I refused to tell them I said that I was old enough to make the decision and didn't want them to know. Instead, I told my parents that I had a bad bleed in my ankle; I never mentioned the fact that I was close to dying. Dr Anderson wanted me to ask my parents to come to the hospital so that she could explain the situation to them, but I said no, no more explaining.
- 37. While I was in hospital in 2003 they tried different anti-viral tablets to make me better and constantly swapped the medication, but nothing would stay down. The last week that I was in the hospital they gave me a brand new tablet on Wednesday, and by Friday I knew that the medication was finally working because my ankle got better and food started staying down. I cannot remember the name of the medication I was given. I was released on the following Monday and although I had to come back the following day for a check up, I was getting better and better. A week later I was walking again and a few weeks later I was back at work. They did more blood tests and told me that my viral load was at zero. From that day to now, the HIV viral load hasn't risen again.
- 38. The various HIV medication I have taken gives you side effects such as making your face flushed and swollen and your head thump, but after a while it goes away. When I first started taking the HIV medication I had to take 8 tablets a day and the side effects were very severe I would vomit and constantly feel extremely nauseous. I was meant to take the

medication on a full stomach, but this just resulted in me being violently sick and vomiting the tablet up. I therefore started to take it on an empty stomach instead. Again, I can't remember the name of this medication. There were so many different and new drugs that they tried at first.

- 39. As time progressed and I tried newer medication the side effects got milder. I have been taking a new drug called Symtuza for the past 7 months, and the side effects are very mild. The drug keeps my HIV viral load down to nil, so if I have a blood test it would come back clear. However if I stop taking it, my viral load will probably go up again. There is a lot of it that I don't understand, probably because I don't want to understand and don't ask the doctors about it.
- 40.1 don't think that the doctors could have done anything more or offered me any more treatment when they found out that I had HIV, because they didn't know much about HIV at the time. It was only when rock stars and film stars were dying of it that HIV became widely publicised and the media put a spotlight on it. I know that I had never heard of HIV or AIDs until 1985, so unless they knew about HIV already for years before and covered it up, I don't think there was anyway that the doctors could have known about it or offered me any other treatment earlier. I don't think that anything more could have been done.
- 41. Prior to ending up in hospital in 2003, I actually had a blood test in November 2002. There had been confusion in the lab and the results of that blood test were lost. Usually, the doctor said that no news was good news, so if I didn't hear from them after a blood test it meant that everything was fine. However when I went into hospital in 2003 they realised that the results for the tests taken the previous November had been lost. I wonder whether they would have known that something was wrong sooner if they had not lost those results, but there is no way

of knowing if it would have made any difference. The doctors and nurses were 'first class' and really did their best. They were not at fault and it was just this one error that happened, so it didn't bother me.

- 42. When I was first diagnosed with Hepatitis C in around 2003 I was not offered any treatment but I think that is because no treatment existed at the time. I think that the nurses and doctors did their best and did a good job, because if at the time there was no treatment available for the Hepatitis C then of course they couldn't offer it to me. I was offered Hepatitis C treatment probably around 15 years ago, but at the time I refused it because I felt healthy and my liver was fine.
- 43.1 only started treatment for Hepatitis C sometime around June/July 2018, but I cannot remember an exact date. I was reluctant to have treatment because I had scans and my liver was healthy, so I didn't see the point in fixing something that wasn't broken. However, the doctors said that it was better to take the drugs and have the treatment at the time while my liver was in good condition as opposed to waiting for it to deteriorate. I eventually agreed because the treatment involved just one tablet a day for three months. I can't remember the name of the medication that I was given.
- 44. The doctor explained the potential side effects of the Hepatitis C medication, which included a lack of appetite and being light-headed. However, the doctor also explained that 90% of people do not experience side effects, and I personally did not experience any side effects from the tablets.
- 45. That was the first and only treatment I have ever received for Hepatitis C. It was a three-month course of treatment so I would have finished the treatment sometime around August 2018. After I finished the treatment course, they took my blood and tested it. The results showed

that I had cleared the virus. They did another test 12 weeks after I had completed the treatment and the results again came back negative. I will need to have another test in a year to see if I am still negative for Hepatitis C but I have been told that it has been cleared.

- 46. If I go for any operations, I still have to explain that I had Hepatitis C. I did ask the doctor why I had to tell someone this when my results came back clear following the treatment, but they said that it is just for the health and safety of the staff in the operating theatre. This makes me wonder if I really am 100% clear of Hepatitis C, but they have said that the results were negative so I will just have to trust that.
- 47. Two of my brothers also contracted HIV and Hepatitis C through contaminated blood, as we all used the same batches of Factor VIII to treat our haemophilia while we were growing up. While I seemed to get on okay with the various HIV medication I was given, my two brothers were sicker than I was. They vomited a lot while they were on HIV medication, and the tablets didn't seem to work. They were always sleepy and never had any energy. I don't know if it was my frame of mind that helped me to get up and move and work even when I felt sick. I think that my brothers worried a lot more, and the effect the illness had on their mind is what made them so much more unwell. I never really spoke to them about the HIV or Hepatitis C, because they were feeling really awful about it. I once did try to talk to them about it but I could see them getting really depressed and I knew they were not coping well with it; it was too difficult for them so I stopped bringing it up.
- 48. The first of my brothers died in **GRO-B** in the Royal Victoria Hospital. He was in hospital with AIDS when he died but ended up with meningitis, and this is what ultimately killed him. My second brother died on **GRO-B** He had numerous stomach

ulcers, and the medication he was on caused all of the ulcers to burst in the middle of the night and he died in his sleep. He too was in hospital with AIDS, but the doctors said it was the bleed from the ulcers that actually killed him. In both cases, there was nothing that could be done for them because the HIV had progressed so much and they had developed AIDS. Both of my brothers passed away **GRO-B GRO-B**

- 49. The death of my brothers really hurt me, and it really affected my mother because she blamed herself for giving us haemophilia. She never really spoke about it because she couldn't without crying, so she stopped talking about it and we stopped mentioning it. I destroyed any newspapers or documents that came into the house that mentioned contaminated blood or HIV because it hurt her so much. I didn't tell my parents about the medication I was on, and I don't think my brothers told my mother and father about the medication either because they didn't want them to worry.
- 50. In 1985, prior to telling me that I was HIV positive, Dr Mayne had come to the house when I wasn't there and told my parents that me and my two brothers had HIV. When I went to see her, I told her that I had not wanted my parents to be informed, but she said that it was better for them to know. I told her that from that point onwards I didn't want her to tell my parents anything, and I did not want any of my medical information to be shared with my family. I did not tell my parents about having Hepatitis C because since my HIV diagnosis and telling Dr Mayne that I did not want any of my medical information to be shared with my family, I never told them anything.

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52.I have GRO-B brothers who live close to me and GRO-B

GRO-B the other two are haemophiliacs who also contracted Hepatitis C through contaminated blood. Both of them were treated for Hepatitis C at least 10 years ago with injections they had to take on a weekly basis. The medication they took was different to the medication that I took for Hepatitis C in 2018. One of my brothers got very sick from the Hepatitis C medication and vomited a lot. I saw him quite often when he was taking the treatment and I remember that it really affected his mood. He was quite crabby and easily irritated at the time.

- 53. The impact of receiving contaminated blood affected most of my family in someway somewhere along the line. My sisters still keep track of my two deceased brothers' birthdays, and reflect on how old they would have been if they were still alive. One of my other brothers thinks a lot about my passed brothers and sometimes wonders whether it is because of a sin that people have to die before their time. He worries a lot, and this is why I do not want them to know that I am engaging with the Inquiry and giving this statement. They would think something was wrong and check in on me all the time. I don't want my family to worry about me.
- 54. Prior to knowing that I had HIV, I was with a woman for four years and we were planning on getting married. When I was diagnosed with HIV, I walked away from it all and told her that I had to go GRO-B
 GRO-B even though that was not true. I just couldn't tell her the truth because I was worried she would walk away from me first, so I made up an excuse instead. She never knew about the HIV and she doesn't know to this day. She still lives about 5 miles down the road and is now married and has children.

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- 55. There is definitely a stigma with HIV, and I have never told anyone in my life about it. Only certain people in my family know about my illness, such as my parents and brothers, but my two youngest sisters have no idea. I am not sure if my third sister knows or not. No one outside of my family knows. If I had to tell people I think I would feel worse. I don't think there is any reason to tell people because I am not cutting my finger and spreading blood everywhere. I don't go up to people and ask them if they are unwell or if they have cancer, so I don't think people need to know what is wrong with me. It is easier for me to deal with having HIV by not telling people than it would be for me to tell people.
- 56. In 1986 I had a stomach ulcer that burst and I went to the Royal Victoria Hospital. They put me in a side ward to prevent contamination, and the doctors, nurses and even the cleaner would come in wearing masks, gowns and gloves. Some of the doctors and nurses didn't want to take my blood because they knew that people in the side ward had infectious diseases. Even the cleaners had obviously been told to dress a certain way and be careful around me in this ward. Being treated this way was one of the most difficult things. Dr Mayne was annoyed that people were treating me like this, so one time she came in and threw her gloves and mask away and took my blood herself to show others that they wouldn't get contaminated just from touching me or getting a bit of my blood on them she broke down the barriers.
- 57. Dentists have been really bad in dealing with the fact that I have HIV. I was initially treated at the Royal School of Dentistry in Belfast. That was where patients from the Royal Victoria Hospital were referred to as it was meant to be a specialist dentistry practice for haemophiliacs. I had gone to the Royal School of Dentistry since I had my first teeth. When I was diagnosed with HIV, the Royal Victoria Hospital declared this to the dentist for me. It was at that point that they treated me really badly. From that point onwards, if I had an appointment at 10 o'clock

the dentist would treat all of the other patients first and push my appointment back, sometimes by hours, days or even weeks. On one occasion the dentist checked my teeth from really far away, didn't touch me at all and just said, "*yep, your teeth look fine*". I also couldn't have any anaesthetic injections during dental procedures because it could cause a bleed that could spread to my brain. As a result, they would just pull teeth out when I needed them taken out, without giving me any pain relief.

- 58. I think that the Royal School of Dentistry were worried about HIV and Hepatitis C and the possibility of contaminating themselves or other patients. I think that the fact that I was a haemophiliac was also a worry for them. The treatment I had at the Royal School of Dentistry made me very angry because sometimes I would drive for an hour to Belfast and wait all day to have nothing done. I would then have to drive 45 minutes back up the road and I would just think about having HIV, and how I was being treated like a criminal because of something I have no control over.
- 59. Approximately 25 years ago, from the late 90s, I started going to a private dentist instead. I told that dentist about the Hepatitis C, but I did not mention that I have HIV. When I told him about the Hepatitis C he told me that all of his instruments were heat treated and sterilised and so there was no chance of anything being passed on to other patients. Not telling them about the HIV was the only way to get past the stigma. The private dentist treated me completely different, and I have received much better treatment.
- 60. For some time when I went to see Dr Benson at the Belfast City Hospital, he would ask me why I stopped going to the Royal School of Dentistry, as this was meant to be a specialised dentistry practice for haemophiliacs. However, when I told him about the treatment I

experienced when I went there he understood and said that he probably wouldn't go back either if he had been treated in the same way.

- 61. If I go to a general practitioner (GP) near my home, I don't tell them about my HIV and Hepatitis C infections. I once had food poisoning and went to the GP, but I did not tell her that I was a haemophiliac with Hepatitis C or HIV because I didn't think she needed to know. I just told her that I had cooked something badly, described my symptoms, and told her that I thought I had food poisoning. She just took my word for it and gave me a prescription to help with my food poisoning.
- 62. Seeing the way the dentist at the Royal School of Dentistry had treated me, and how the nurses and doctors dressed and treated me in 1986 when I was in the side ward at the Royal Victoria Hospital made me not want to tell people about my viruses. If that was the way the dentist and doctors had acted, imagine how someone else would react if I just walked up to them and told them. I wonder if I told someone how I got it whether they would really believe me; whether they would believe that I really got it from contaminated blood or would they think that I was actually a drug user or homosexual.
- 63.I don't think that Hepatitis C has the same stigma attached to it as HIV does at all.
- 64. At the very beginning when I was taking the medication, it affected my ability to work on the farm because I would feel sick and nauseous and have to sit down. The side effects made it more difficult for me to work between the ages of 25-40 than it does now, as the side effects of the medication I now take are less severe. I also don't think about it that much anymore. When I was 25-40 it would play on my mind more; while I was fine when busy, if I sat down and watched the news and

saw something about AIDS I would think about it even if I tried not to. I don't know why it bothers me less now; maybe I don't have the same interest in life anymore.

65. If I didn't have HIV and Hepatitis C, I don't know if I would still be working on the farm here at home. When I left school I was a mechanic for about 10 years, and during this time I went to **GRO-B** for three years. This was between the ages of 16-28. Most of the people I worked with stayed in **GRO-B** and some went on to work in Australia. However I came home after three years because in those countries you have to pay for HIV medication and you don't have to here. My decision to come home was because of the HIV treatment available here. I do sometimes think that things may have been different if not for the infection and I might have ended up in Australia doing what they are doing, but maybe not – who knows.

Section 6. Treatment/Care/Support

66. While I do formally have a GP called Dr GRO-B I never really go to the GP because I always go to Belfast City Hospital for my blood tests and check ups. The hospital is a gro-B mile drive away from my home and it isn't always easy to get to my appointments on time because the roads have become busier over the years. The car park is always full and I sometimes have to wait for an hour before I can get a space. The constant road works and traffic means that I have to leave an hour earlier than I did a year ago to get to my appointment on time and ensure that I can get all my blood tests done. However, actually making an appointment with the hospital is easy because once I say that I am a haemophiliac and that I am unwell they give me an appointment right away, I don't have to wait.

67. In 1985 when Dr Mayne first told me about the HIV she offered me psychological support and counselling. When I was about 25 I went to a one-to-one session with a psychiatrist and I listened to the psychiatrist for about 5 minutes before I left; I felt like it would make my mind worse and make me depressed. I told Dr Mayne never to send people like that to me again because it was depressing. Fixing my tractors on my farm is enough – that's my therapy and my way of dealing with how I feel about it all. It takes my mind off everything and if I need to, I can vent there, as no one else is around to hear me.

Section 7. Financial Assistance

- 68. I received payments from both the Macfarlane Trust and the Skipton Fund. I knew about these schemes through the Haemophilia Society, and I think that the Haemophilia Society must have given them my details, because I never contacted them first, they contacted me first.
- 69. When the MacFarlane Trust contacted me about 30 years ago, they told me that they would give me a certain amount of money per month. They sent me a letter with a reference number in the top corner, and paid the money directly into my account each month. It was very easy for me to get the money, and it started out as a small amount and increased over time. I can't now remember how much I got each month.
- 70.1 must have had to fill out forms and provide the names of my doctors and the hospitals I attended to the Macfarlane Trust, but I don't remember doing this. I think that the Haemophilia Society must have gotten all of the information from the Bridgewater Street City Hospital for me and given the MacFarlane Trust my information. I can't remember going to any doctors or hospitals to get things signed myself. However, as it was such a long time ago I can't remember exactly how

it worked. The MacFarlane Trust initially gave me a lump sum payment of £20,000. I can't remember when I received this, as it was a long time ago. I would then get a bit here and there on top of the monthly payments, for example payments for heating at winter or a Christmas bonus. I am not sure exactly how much these sporadic payments were.

- 71.I received money from the Skipton Fund about 10 years after I received the lump sum payment from the MacFarlane Trust. I think I got two lump sum payments of £20,00 from the Skipton Fund, and no monthly payments from them.
- 72. When I received money from both of these funds, they told me that I was receiving it because of my infection with HIV and Hepatitis C. I felt like it was blackmail, even though they didn't say anything like that. I just felt like these payments were a way of keeping us quiet and appeasing us, all the while letting people like my brothers die. I felt it was a way of keeping it all quiet and avoiding a public inquiry, because once everyone quietly died off there would be no need to have a public inquiry. This is my opinion because I don't understand why they are giving me money for something they say isn't their fault, and why do they keep giving me money here and there and prolonging it. I think they just give us the money to keep us going and to keep us quiet until we eventually die.
- 73. Now the MacFarlane Trust and Skipton Fund have been changed and the payments come under the Infected Blood Payment Scheme for Northern Ireland. I still receive payments from this new scheme every three months. Again, I do not know exactly how much I receive every three months as I don't keep track of it. Sometimes I get what they call a 'top up' in between. The top up is around £400.

74. The money that I have previously received from these various funds and the money that I am currently receiving is put into a separate account that I have. My usual income does not go into the same account. I am saving all of the money I have received from the various funds and schemes for if something comes up or if there is an issue in the future where I need the money. I like to just keep it there and not touch it. It is there for the future just in case I do need it, but for now I am happy and able to live from my usual income.

Section 8. Other Issues

- 75. If I am being honest, I don't see any beginning or end to this Inquiry. I don't think that the government will ever own up. The people who have died are gone now, so how is the government going to apologise to them?
- 76. I knew haemophiliacs who committed suicide when they found out that they had HIV. When I was about 25 years old, one haemophiliac who was a few years younger than me jumped off a bridge the day he found out. I think it was because he couldn't cope with it, he couldn't cope with the stigma. Another boy shot himself. Both of these boys went to the Royal Victoria Hospital and were in contact with the Haemophilia Society, so this is how I knew them. There may have even been more who committed suicide – I only knew these two.

Statement of Truth

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

Signed	GRO-B
Dated	6-5-2019

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