Witness Name: GRO-B
Statement No.: GRO-B
Exhibits: none
Dated: 17th April 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 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 1940 and my address is known to the inquiry. I am married and have been married for fifty four years. I was self employed as an GRO-B before my retirement in 2002. I intend to speak about my experiences of becoming infected with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

Section 2. How infected

2. I was diagnosed with severe haemophilia A in 1945 and I developed a Factor VIII inhibitor sometime in the 1960s or 1970s. I couldn't say how often I

attended hospital for my haemophilia treatment but I would estimate more than five times a year. I received fresh frozen plasma, cryoprecipitate, porcine AHG, FactorVIII, DEFIX, FEIBA and NovoSeven. I do not know which of these products led to me contracting hepatitis C. I was under the care of Prof Girdwood, Dr Davies and Dr Ludlam from the 1950s to the 2000s

3. In 1994 I was told I had hepatitis C which I later found out was genotype 1A. I was in hospital after a motor accident when I was informed by Dr Ludlam. I wasn't very happy about it but there was nothing I could do, I just hoped to get treatment to get rid of it. While in hospital I started treatment with interferon which was stopped after six weeks because it wasn't working.

4. Nothing else was done about it for a number of years. I was feeling fine physically, I didn't have any problems. Most of my problems came from haemophilia and my inhibitor to factor VIII. Hepatitis C didn't cause much trouble at all day to day. Apart from the fact that I was infectious, that made a difference. I didn't broadcast my infection, I didn't talk about my haemophilia either, I just got on with things. There have been times throughout my life when I was very ill, but they were few and far between, I just got on with my life.

5. Dr Ludlam explained that Hepatitis C was unlikely to cause problems for many years, however, I could go on to develop cirrhosis or cancer of the liver in the future. I expressed disappointment about being infected. I remember telling him that I thought it was better than being infected with HIV. It didn't seem such a bad thing at the time. He gave no estimate of when I had been infected or how long he had known. He was always very good and I got on well with Dr Ludlam and all his staff.

6. I don't know if I should have received information earlier, I don't think so. Sometimes it is best not to know, and worry about something, for which there is no treatment anyway. It was a very long time ago.

7. My wife attended a meeting on my behalf in December 1984 about HIV held at the Edinburgh Royal Infirmary. This meeting discussed HIV and the risks of cross contamination. When I was told of my diagnosis of hepatitis C in 1994 I applied this information to hepatitis C as well, even though hepatitis wasn't raised in the 1984 meeting.

Section 3. Other Infections

8. I think I had hepatitis B at one time, when I was under the care of Dr Davies in the1960's or 1970's. I was very badly affected with jaundice, my skin turned quite yellow. What caused that I don't know but I think it was one of the hepatitis infections. I don't remember if Dr Davies spoke to me about it, I don't think it was really discussed. It was just one of those things. I also remember having night sweats and rigors during some treatments and taking Piriton before treatment to try to prevent them.

Section 4. Consent

9. I think all haemophilia patients blood was tested without their knowledge. That has become obvious from the inquiry now. Nobody really knew they were being tested. I felt it was a natural thing for them to do. Whether they needed to tell you or not is something I leave for the inquiry to rule on.

10. I think the doctors did avoid giving out information about the risks of new treatment trials because they were unknown. Obviously with me, it would be some sort of blood product. I wasn't aware that I was given a pig's blood product until afterwards. It was on my haemophilia card that I received porcine AHG. I was very ill at the time and it was probably used as a last resort. I survived so I was grateful that that treatment had worked. On another occasion, while in hospital, I recall having a skin test done on my arm. This test was comprised of about a dozen pricks on my arm and then they waited to see if there was any redness. I wasn't aware what each needle represented, it was like an allergy test. They must have told me something at the time when they

were doing the test, but I didn't pursue it. I have never found out what the test was for.

Section 5. Impact

11. I don't think I suffered as much as some people with hepatitis C I didn't suffer at all really. I just know I had it and that I had to be careful if I was bleeding, to not spill it on anybody or infect anybody. That was a bit of a burden to carry. My lifestyle was such that I wasn't playing any sport or in a position to bleed on anyone but it was always in the back of my mind. On a positive note I was fortunate in 2004 to get hip replacement surgery despite my hepatitis C status.

12. I have recurring skin itching. Since watching some of the witnesses during the inquiry, it seems quite often to be blamed on hepatitis C. The skin itch is a problem, it's quite severe at times. It comes and goes but it gets at bits of your skin and you find yourself scratching yourself. My arms can get quite red with blotches. Other witnesses have put their itch and blotchiness down to hepatitis C and since hearing that, I have as well. Feeling very cold is also a problem but this may be due to my age.

13. Some people have said that their deafness has become worse. My deafness has definitely become progressively worse. I wear two hearing aids and when I take them out, I can't hear much at all and I really rely on having them. It could be me just going deaf. I can't say that it is definitely because of hepatitis C. It's only because other witnesses have said it that I have started to think about it.

14. I regularly had six monthly blood tests and ultrasound scans of my liver. The scans of my liver have been discontinued. I don't really know if I would want any more ultrasounds now, I have gone through it for years. I don't really think it's going to make much difference to me at my age. I have also got a recurring pain in my lower right rib area that I've mentioned to my doctor. They think it's muscular pain but I don't know if that's anything to do with hepatitis C.

15. I was diagnosed with ischaemic heart disease about fifteen years ago and my blood pressure and heart condition have been controlled with medication since then. Whether that has anything to do with hepatitis C, I don't know. My coronary arteries are also slightly blocked and that has caused angina from time to time. I may have had these heart conditions anyway, whether I had hepatitis C or not.

16. In 2003 I was transferred from my local dental practice to the Royal Infirmary dental department. My local practice hadn't been doing proper hygienic treatment in case they caused bleeding. It was only when I was transferred that my gum hygiene improved.

17. I was at the Western General in 2008 for a cystoscopy and they had to use an older scope that would then have to be destroyed after the procedure because of the risk of cross infection. That meant I had to come back later when they had a scope they could use for me. There was another time at the ENT Department where they wanted to put a scope into my nose to look for a polyp and they couldn't do it as there wasn't a scope available for me. Again I had to come back another day when they had an older scope they could use on me and then destroy. As far as I am aware, equipment used on me was destroyed after being used only once, because of hepatitis C. There was a time about thirty years ago when I cut my finger using a saw and I needed a couple of stitches. I went to the Haematology Department at the Royal Infirmary Edinburgh but they had nothing there to do the stitching with, so I was accompanied by Dr Cuthbert, one of the Haemophilia doctors, to Accident and Emergency. The staff there seemed to be keeping their distance and were reluctant to get involved so Dr Cuthbert ended up doing the stitches himself, but I think he was looking for someone else to deal with it, but nobody would. I have not experienced any other adverse reaction to my infected status, no one was every nasty. I have been very fortunate.

18. My wife says our life has been affected quite a lot because there was always my fear of passing on the virus to her. She would say that I didn't hug and kiss her as much as I might have otherwise. That goes back to the first meeting in 1984 about HIV and the safety advice given which included the use of condoms. This affected our marital relations.

19. In 1984 when I started to be more aware of the risks of infection my son was six years old. I don't think he understood much at that age. I didn't make a big thing of it, I didn't want him to be scared to touch me. I couldn't do a lot of sporty things with him because of my haemophilia but things like hugging might have been different. It's difficult to say because it was so long ago. I've never experienced any stigma about my haemophilia or hepatitis C. I think that is because so few people knew. I don't think my son had anything said to him because of my infected status either. I don't know if he spoke to his friends about it.

20. My hepatitis C didn't affect my employment before retirement at all.

21. My hepatitis C didn't affect my ability to acquire life insurance as this was achieved prior to 1980. I got travel insurance in the past which was included in the holiday package. I haven't been abroad for a holiday since 1998 so I don't have any recent experiences of trying to get travel insurance.

22. I don't believe my infection has adversely affected my marriage. My wife has willingly helped me when needed. She has said she married me knowing I had haemophilia. What has happened since then doesn't matter to her, because whatever life threw at us we were going to get through it together. Over the years my wife has continued to help me and she wouldn't have wanted it any other way. I have been very lucky.

Section 6. Treatment/Care/Support

23. The interferon treatment I had in 1994, lasted around six weeks and it was not successful. In 2008 I had treatment with interferon and another medication that I cannot recall the name of. That didn't work either. I had a successful treatment in 2016 with Viekirax, Exviera and Ribaviron. I had to keep asking to get the latest treatment after the previous failed attempts and I was told by Prof Peter Hayes, Hepatologist I would have to wait a bit longer. They said they first wanted to use the supplies of the new treatment for patients who were more severely affected, but eventually I asked to be treated as well. I received treatment at the Hepatology Department in Edinburgh and it was successful. The treatment lasted from July until September 2016 and there was no virus detected after six months. I had a fibroscan done before and after being treated.

24. There was difficulty accessing treatment. I was told it was expensive, over £40,000 for each patient and it would be better if I could wait as they were prioritising other patients. I thought that was fair enough, I wasn't suffering from the hepatitis C in any way that I was aware of, so was able to put it off. But at the same time, I knew it would be better if I could get rid of it. I don't know if it's fair that they told me the price, I was also made to understand that the supplies they had weren't enough so I would have to wait. If I had been experiencing more hepatitis related symptoms at the time maybe I would have pushed for treatment more. I just knew it was something I needed to deal with, I did and got it cleared.

25. There were no real side effects, physically or mentally from treatment in 2016, everything was just fine. I took it, I was neither up nor down with it and got through the twelve weeks without a problem. I was very pleased that when they did the tests after the treatment that there was no virus detected. There were no real problems with the treatments in 1994 or 2008 either, I didn't have any of the problems with interferon that I've heard about since.

26. No counselling or psychological support was offered when I was diagnosed with Hepatitis C. I know it is now available at the Haemophilia Centre in Edinburgh but I have not needed to respond to this. I am from an age where you just get on with things. I think all this counselling is a more modern thing,

Section 7. Financial Assistance

27. It was not easy to find out about financial assistance. I did not know that money was available for patients with hepatitis C from any of the different funds until I recently attended a Haemophilia Scotland meeting. People there were talking about getting £1,000 for their heating and different things but I was not aware of any of this. I learned more from watching the inquiry hearings online, than I did from anywhere else.

28. In 2004 I received a Stage 1 ex gratia payment of £20,000 from the Skipton Fund. In 2016 I received an additional Stage 1 payment of £30,000 also from the Skipton Fund, for those infected in Scotland.

29. When SIBSS was set up in 2017 I received a form to complete. They asked me to state whether I needed any help and how hepatitis C had affected me. I took the view that it hadn't affected me very badly, it has always been haemophilia and the inhibitor to factor VIII that has affected me, not hepatitis C. I know there are people who have had problems with hepatitis C and have had their life threatened or taken by hepatitis C but I've not had that. So I didn't need to ask for help. I do now receive a yearly payment of £1,000 from SIBSS and I have received two payments so far.

30. I don't think my income has been as good as it might have been if I had not had haemophilia and been infected with hepatitis C and I don't have a good pension now. My pension provision is low because I have always

believed I would not live a long enough life to reach pension age and consequently did not put much money into my pension funds. My wife has a work related pension. So on the whole, we are not too badly off and we have enough money to manage.

Section 8. Other Issues

31. It would be nice if something did come out of this Inquiry as not a lot came out of the Penrose Inquiry. In my view it was six years of wasted money and wasted time. It was only the lawyers who made any money out of it. The cost of this current Inquiry will be considerable and I hope it will result in a comprehensive report/result which will be accepted by all and bring this whole sorry episode to a conclusion. Although initially reluctant to participate, I am doing so because during the course of the Inquiry, Sir Brian Langstaff has often asked that further witness statements be submitted and my wife took the view that my experiences should be part of the Inquiry and I finally agreed.

32. I wish to be anonymous for this statement.

Statement of Truth

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

Signed **GRO-B** ______________

Dated May 11, 2020