Witness Name: GRO-B
Statement No.: WITN2299001
Exhibits: none
Dated: 30th 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 23rd April 2020.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1966. My address is known to the inquiry. I am married to GRO-B, we have been together for twenty four years and married in GRO-B We have one daughter together. I am currently unemployed after leaving my job as a GRO-B GRO-B in 2003 due to the effects of my hepatitis C infection. I intend to speak about my experience 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.

2. I wish to remain anonymous for this statement.

Section 2. How Infected

3. I have mild haemophilia, I do not know whether it is haemophilia A or B.

4. I know that I received cryoprecipitate for my haemophilia. I do not remember if I received any other blood products in relation to my haemophilia.

5. I cannot remember exactly where and when I was treated for my haemophilia. I know I was treated at Yorkhill Children's Hospital as a boy and then Glasgow Royal Infirmary when I was older.

6. I don't know the names of any of the doctors that treated me for my haemophilia.

7. There was no information given to my mum or myself about the risk of infection from the blood products I was receiving. When I was first told that I had hepatitis C, the way the doctors worded it, was as if I was meant to already know. I went back home and I phoned Mum to tell her and she didn't have a clue what I was talking about.

8. I do not know how I was infected with hepatitis C and I have never received a proper explanation. When they initially diagnosed me, they could not give me any dates I had received the infected blood products or any reason as to why I was infected. I have never been afforded a proper explanation.

9. When I was told I had contracted hepatitis C, I was taken into a room at the Haemophilia Unit at Glasgow Royal Infirmary. I spoke with Professor Lowe and Professor Tate and they explained that I had contracted hepatitis C. I do not know what date this appointment was. During this consultation it was phrased that I knew that I had hepatitis C, for which my immediate response was that I had never been made aware of it before. They went on to try and explain to me, what it was and how it would attack my liver. I asked them if I would be compensated for being infected by the NHS to which their response was a simple no and that was it. They just ended the discussion there.

10. I was not given enough information to understand the infection, definitely not. Especially for something like that, it's quite major. They were very vague and it came across that they were covering up as much detail as possible.

11. They could have told me when they were giving me the blood products that there was a risk with receiving them. They waited a long time to tell me in my opinion.

12. I thought the way they told me about my infection was very uncaring and unprofessional. It was as if they were saying, we have contaminated you with a killer disease, run along now. I think it's a disgrace the way they have handled it.

13. All I was told was that I could possibly pass it on to my partner. I did not have a partner at the time so I don't know if I took it all in at that point. I think they told me how the infection could be passed on as well, but it was a long time ago, I cannot remember the specifics.

Section 3. Other Infections

14. I am at risk of having vCJD. I was told about this risk at the same appointment I was given my hepatitis C diagnosis.

15. I think I was infected with hepatitis B at one point as well. It was never explained to me, but there was a time when I started routinely receiving hepatitis B booster injections at the Glasgow Royal Infirmary. I cannot remember the dates I received these injections. I could never understand why they were giving me these injections. To me, as a child, when I used to read the commando magazine or watch war movies, hepatitis was something you got in the jungle. I didn't know anything about hepatitis otherwise. I didn't have a clue what that was for, they didn't explain it which leaves me even today, not being sure whether I have had hepatitis B or not. To me, hepatitis B had no relation to my haemophilia. Eventually I stopped receiving these booster injections, but why they were stopped was not explained to me either.

Section 4. Consent

16. I definitely think I was tested without my knowledge. They took bloods from me all the time, haemophiliacs were like a giant clinical trial, as far as I am concerned. I did not ask for any of this. Nobody has ever explained to me that there was any possibility of getting these diseases.

17. Haemophiliacs were cheaper than monkeys. After what I have read about the infected blood scandal, it's become clear that we were just a human experiment. When they take blood, even now, I don't ask what they're taking them for. You just let them get on with it. They could have taken whatever they wanted and done whatever they wanted with it.

Section 5. Impact

18. My infection made me feel very frustrated. It brought out a lot of anger in me. It has caused a number of problems for my marriage. Mentally it has been very emotional dealing with the infection, it has been very hard for me.

19. Physically, the infection caused a lot pain, especially joint pain. I could not explain the joint pain, I didn't have any bruises or anything like that. There were times where I struggled to get out of bed because of the pain in my joints. It affected my ankles, knees and elbows, they were all very sore. It made parts of my life very difficult. I couldn't say when the joint pain started, but it peaked in the 1990s.

20. I wasn't different from any other GRO-B man in the 1990s. I liked to go out for a drink. I did not go overboard with drinking, but I liked to have a drink on Saturdays, when I went to the football. What I did experience though was intense three day hangovers. I could never explain why I was suffering that much from having a few drinks. Obviously I know now that it was because my liver was under so much pressure. Whenever I went in to the hospital, they

would ask how much I had to drink. I would tell them I had six to eight pints on the odd Saturday and they would call that binge drinking. I told them that was only something I did every two or three weeks. To me, they were trying to link any potential liver damage to me having a few drinks on a Saturday and not to the infection.

21. I have always been a big lad but I have always been physically fit. I played a lot of football growing up, despite my haemophilia. I used to play five-a side and play in a Sunday league as well. That became physically impossible because of my infection. I was so drained and so tired. I put a lot of weight on after I stopped playing and I couldn't explain why, it was very confusing

22. I still suffer from brain fog which I believe is another symptom of the infection. The brain fog can cause confusion for me at times, it affects my memory. I can't really remember when the brain fog started but it would have started in the 1990s along with the joint pain.

23. Back then the brain fog and the joint pain just seemed normal. I couldn't explain why I was like that so I just thought it was normal for me, it was a pain to be honest. It made me angry. Mentally, I hated the world. I wanted to fight the world, I wanted to fight everybody. That was totally out of character for me. I had a genuine chip on my shoulder about people and I couldn't explain why. I felt hatred and again, I don't know why. I just had so much anger and resentment that I did not understand. It was like I was a different person. Looking back now, and having the information to hand about the symptoms and the treatments, I can look back and know why I felt the way I did.

24. I started an Interferon treatment for my hepatitis C sometime in the 1990s at the Glasgow Royal Infirmary. I do not know the exact date I started this treatment. The Interferon was horrific. I felt it made things worse for me. I was angrier and it made me depressed. I suffer from psoriasis and that really flared up during the treatment. I had to stop the Interferon treatment because of it, I could not continue with it. I was only taking it for around 6-8 weeks before I refused to continue. I couldn't handle it, it was all too much.

25. I was eventually put on Harvoni to treat my infection and that seemed to do the trick. I started the Harvoni treatment about four or five years ago but I cannot remember the exact date. It was a twelve week treatment at Glasgow Royal Infirmary. I used to go in to the hospital for the treatment but eventually I just went to the chemist to get the Harvoni and I could take it at home. The Harvoni treatment did not give me any of the issues I had with Interferon, Harvoni was a lot easier to manage. That cleared the infection and I am told the infection is lying dormant now.

26. I did not have any problem accessing the Harvoni treatment or the interferon treatment. I am not aware of there being any other treatment options that I could have been available to me in between.

27. When my wife and I were trying for a child. We had various problems trying to conceive so it was recommended that we try IVF. I do not know who we saw about it but we went to the Glasgow Royal Infirmary to see if IVF was a possibility for us. We waited 3 years for a chance at IVF and I explained from day one that I had hepatitis C. When it came time for us to start the IVF, we were then told it wouldn't be possible because of my hepatitis C. For 3 years they built our hopes up, all for us to be told it couldn't go ahead because of my infection. That was a hammer blow to us. It was a really low point. We eventually managed to get IVF but we had to go through the Haemophilia Unit, which led to us being given one shot of IVF. Thankfully, our one shot worked and we now have our daughter. We were very lucky, but without the Haemophilia Unit, we might not have been able to have a child at all.

28. I remember having a varicose vein around ten years ago and I was refused treatment for it. Again, like the IVF, there was no explanation given. I can only presume that it was because of my hepatitis C status. They were fully aware of my infection when I went to see them about the vein initially. I went to Queen Elizabeth University Hospital to have it treated but when I went there they just told me they were not going to do it.

29. My dentist is based at Glasgow Royal Infirmary. I suppose I have never had what you might call a 'normal' dentist but I don't know if that is because of my haemophilia or my infected status.

30. My infection has been a strain on my life. It has been difficult for me to deal with. My social life is basically nil these days, it feels pointless even trying to have a drink because it would just leave me deeply unwell afterwards. I have basically become a social recluse, I never really go out. I have had periods where I have been very depressed. I think my whole family has experienced periods of depression at some point because of this. Both my wife and my daughter at times have had to walk on eggshells because of how I was doing mentally. I had frequent mood swings, it was a living nightmare.

31. The stigma around the infection was embarrassing. I had to make up a lot of excuses to hide my infection and explain why I could not go on nights out. It might sound crass but to me, hepatitis C was something that drug addicts got. So I didn't feel like I could tell anyone because I would be labelled a drug addict. I was embarrassed, I just felt ashamed because I had contracted it.

32. It was a struggle to continue working with my infection. I honestly could not keep doing my job, I had to give it up. I strug6igled with daily life, I struggled to even get out of bed in the mornings. I was aggressive and I was angry, I was very irritable and confused a lot of the time. It made doing my job impossible.

33. Leaving my job had a big impact financially. I had a good job and there was always a lot of overtime available. Due to being so exhausted with the infection I was not able to do the amount of overtime I would have been able to before. That had an impact financially, and it put pressure on me. Not only from my colleagues but from the management. They did not know about my hepatitis C. They kept asking why I was not doing any overtime. I tried to explain to them that I was so tired I couldn't do it, but they did not understand. That became a recurring argument with the management. I lost a lot of money through those problems with my job. I probably lost out on the chance of

promotion as well but that is something I'll never know. I just feel I missed any opportunity to move up the ladder because of how the infection affected me.

34. Being infected changed how I was as a person. There are still members of the family that I do not talk to because we have fallen out. I have had a lot of confusing, painful arguments with my family. The way the infection affected my behaviour caused a lot of that.

Section 6. Treatment, Care and Support

28. The Haemophilia Unit have been superb, I can't fault them at all. There has not been a lot of support to be honest but the unit has given me as much as possible.

29. I cannot remember if support or counselling was offered through the health service, I do not think it was. I just had to pursue it myself. I currently get counselling with Grainne O'Brian, I started seeing her at the start of the year. She is based in the Haematology Department in Edinburgh and comes through to see me. She has been a godsend. I found out about her through the internet on the Haemophilia Scotland website.

Section 7. Financial Assistance

30. I have received money from the Caxton fund, the Skipton fund and the SIBSS. I cannot remember how much I received from the Caxton fund but I have received various grants from them. I think I received £20,000 from them initially many years ago when I was diagnosed with hepatitis C. I cannot remember how I found out about the Caxton fund, I think it could have been through the Haemophilia Unit or the internet but I am not sure. I do not remember any difficulties when I went through the application for financial support with the Caxton fund.

31. From the Skipton Fund, I received £30,000. I think I found out about Skipton through the Haemophilia Unit. I did not have any problems whatsoever in applying to the Skipton fund.

32. I now also receive £27,000 per year from the SIBSS. I heard about them through the Haemophilia Unit. I had no issues with applying to the SIBSS, it was quite easy.

33. I've had no problems with the various funds, they've always been quite good with me. I know some people have had problems but I've not had any.

Section 8. Other Issues

34. I have nothing else to bring to the Inquiry's attention.

Statement of Truth

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

Signed GRO-B ____

Dated Jun 11, 2020