Witness Name GRO-B
Statement No.: WITN2213001
Exhibits: none
Dated: 8th February 2019

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 5th 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 1947. I am currently retired. Prior to retirement GRO-B I live with my partner GRO-B. I have two children GRO-B GRO-B. I have a stepdaughter GRO-B.

Section 2. How Infected

2. I believe I was infected with hepatitis C during an operation in February of 1985. I required a transfusion during this treatment. This was an operation to remove my thymus gland because of the condition I have called GRO-B. This was at the Southern General. I was under the care

of Professor J.E. Simpson who was a professor of neurology there at the time. I am aware that he has since retired. I do not know how much blood was given to me and I do not believe there is anything in my medical notes to indicate how much blood I was given.

3. It was in 2003 that I was diagnosed with hepatitis C. I had noticed in the media that there was referencing to people who had had blood transfusions having hepatitis C. I recall that was in my dentist was filling out a form and it had a box to tick if you had hepatitis C and I thought that I'd better go to my GP to find out. My doctor had me tested. My GP is a Dr GRO-B is based at GRO-B. Dr GRO-B organised a test and I remember I had to phone back in two weeks and I was told that I was A/B negative . The next day I was told that I had hepatitis C. I suspected as soon as I saw it on television.

4. I remember that I had jaundice-like symptoms a few weeks after my operation back in 1985. There is a letter that I have from Dr Simpson in my medical notes on 20th July 1985 which references this. I do know that jaundice was definitely as a result of hepatitis C and some effect it was having on my liver in the immediate aftermath of the operation. That same letter mentioned I was recovering well from mild hepatitis. This does not specify what kind of hepatitis it is. Dr GRO-B referred me to the Infectious Disease Team at Monklands.

5. It was Dr Nicholas Kennedy who told me more about hepatitis. What he said had more to do with treatment and what might happen in the future. I got the impression he wasn't there to deal with the psychological impact of what I was facing but he was pleasant and amiable. I do feel that the medical information given was adequate but I did feel there was a missing link of having any support.

6. I found out more through an English Infected Blood group who were very nice and gave tips about diets and mitigating the condition through diet. I would have liked someone to talk to about what was going on that time.

7. I do wonder why, in that letter in July 1985, that they say I had mild hepatitis from which had recovered, was not followed up by anyone. I do not know why this wasn't flagged up to me or to anyone else at that time to be followed up. I was initially just distraught being at hospital at the time when I had the operation. I had that fear of going back and I remember the doctor saying that I was very infectious. I thought this was temporary.

8. I recall in 2003 Dr Kennedy talked about other people in the family being tested. He did say it is extremely unlikely that others have been infected. My partner decided not to be tested. I was reassured that it was very unlikely that anyone else had been infected. I do not remember what was said about cross contamination or if any information at all was given.

Section 3. Other Infections

9. I was infected only with hepatitis C.

Section 4. Consent

10. I do not believe that there were any issues in terms of consent or been treated with or without my consent.

Section 5. Impact

11. Looking back there were some symptoms I would now attribute hepatitis C but I did not know what it was the time. As I said I had jaundice in the immediate aftermath of my operation in 1985. I had yellow eyes, skin and urine. I cannot see how this can be from anything other than my operation.

I was at home when I noticed this and I told them at the outpatients' clinic at the Southern General Hospital. I got the impression that they did some sort of test and then a week later I was told that I had hepatitis and I believe they may have said non-A/non-B. Dr Simpson said that it was probably from blood products. I did not appreciate the seriousness of this at the time. I thought it was jaundice, I'd had it then recovered. I did not know there were any implications for the future.

12. I suffered from extreme fatigue but it's hard to distinguish between this being a symptom of hepatitis C or being from my condition that I mentioned, GRO-B. I still get fatigue even now. I've also in the past from abdominal discomfort which I thought was due to the GRO-B medication. The abdominal discomfort has decreased since I had the Hepatitis C treatment, so I now think it was Hepatitis C causing this all along. I also may have had brain fog but sometimes I think that could be down to my GRO-B. From what I understand this is a common symptom of myasthenia gravis GRO-B in itself is a very rare condition.

13. My liver has been damaged by hepatitis C. I was at the Monklands hospital very recently on the Wednesday prior to giving this statement. I get a fibroscan every six months. I have not had any biopsies. The fibroscans have revealed that I have coarsening and scarring through my liver. I believe that it is only when it reaches a certain level that you are considered to have cirrhosis of the liver but I am not at that level at this stage. My levels have fallen since treatment. I understand my level was at a dangerous level at the time of my treatment and could have gone on to the level of cirrhosis.

14. The only treatment I have had was for Sofosbuvir and Daklinza pills. Interferon and ribavirin was offered to me earlier but it was found that this was too dangerous for me to have due to my GRO-B. I remember there was another new drug with ribavirin which was mentioned at one stage. I did not want to take the risk of making myself ill as I had memories of being on a ventilator when I was in hospital in relation to GRO-B

GRO-B I did the full 12 week course of Sofosbuvir and Daklinza and this was successful.

15. My physical symptoms were headaches as well as fatigue and tiredness. I had flu-like symptoms and I was achy, but I found this to be bearable. I was very intensely worried about taking drugs. This last course of treatment would have been a couple of years ago. It would have been January 2017 and I was clear in October of 2017.

16. The main difficulty for treatment was the risk of affecting my autoimmune condition, GRO-B. I did try and see if there was anyone else in a similar situation to me, but GRO-B is so rare as I said that it is very difficult to find anyone that would be in the same situation. I started treatment because I felt I had to take the chance because my liver levels were increasing and this was worrying me. Anything that affects the balance of my immune system would generally be a huge risk. I had the absolute fear of being put on a ventilator again.

17. I would say the mental effects of my condition have been huge. The main focus was on the stigma and a fear of anyone finding out about my hepatitis C. There was no support and I did not know what was available. It was a secret that I kept from friends and much of my family. I think you cannot underestimate the mental anguish that having a condition like this causes. I even spent less time with friends because of my hepatitis C.

18. There was a feeling of self-loathing or low self-esteem. It was a fear of not being accepted or permitted to be involved and a feeling of a shame and a desire to be invisible.

19. I do feel that I am a sociable person but I became less involved socially. I couldn't say it was because of my Hepatitis C.

20. In the past I would have gone on holidays with friends. This would have been just weekends away and things like that. When I found out about my

condition I stopped going on holiday with them. I still meet up with these friends, but for example when we meet at Christmas I have been offered the option of staying with whoever hosts the dinner but I never do stay.

21. I feel that I have constant anxiety with things like specialists, scan results, blood tests, treatments as well as other treatments that were available to me. I do not think I was an anxious person before, not at all. I feel like most of my anxiety is based around my hepatitis C.

22. When I was at a clinical review I was asked about the stigma. I was asked how the stigma affected me and I said that generally I was just relieved at the time of when I had the operation to know that what I had was GRO-B GRO-B because it let me know what was wrong. I don't mind people knowing about my GRO-B but when I got hepatitis C I didn't tell anyone. I feel I have carried the weight of hepatitis C on my shoulders. I'm worried that a conversation will lead back to hepatitis C and I have constantly told lies about why I have been in hospital. My GRO-B was the sort of get out clause I could use as an excuse.

23. Physically I found that I just can't participate in daytrips or travelling or going out on walks because of physical weakness which could be down to the Hepatitis treatment as well as my GRO-B.

24. In terms of other treatment I required I would say that my dental treatment has only been impacted in the sense that I'm always seen as a last appointment either at lunchtime or at the end of the day. I believe this so everything is sterilised. My dentist has been very good about my hepatitis C. She said she treated all patients as if they could have something contagious and was always very careful anyway so my hepatitis C would not have had any impact on her. My dentist is supportive and hasn't suggested any different arrangements. My dentist's name is GRO-B. GRO-B

25. The effect on my work was terrible when I found out about my diagnosis. I was a teacher and I was scared to tell anyone. I confided in my line manager who said that he would make enquiries. He said it was okay to continue teaching but if any child bled or was hurt someone else would deal with this. I felt like I could not continue in mainstream teaching. Up until my diagnosis I would look for promotions and the possibilities of progressing my career. When I was diagnosed I felt I had to become invisible. I did not go for any further promotions and I was generally quite scared to be in the wider world and have that attention. I gave up all chances for promotions and courses. I did not do anything to improve my skills and generally just kept my head down. My condition has hugely stifled my ambition. I lived in fear of being discovered and I had a fear of losing my job. I was a single parent at the time so the pressure was great to be in a job.

26. The posts I did not go for what I could have gone for were as a senior teacher or a deputy or a head. I felt my job could have led to endless opportunities. I was stopped by my fear of drawing attention to myself. I worried if anyone found out it would have gone around very quickly. I do not think I would have ever got a promoted post with my hepatitis C. When I spoke at the clinical review it seemed that anyone with hepatitis C was financially affected by hepatitis C. I started working part-time if I was ill and that was what happened several times. I job shared due to ill health. This has reduced my pension.

27. I believe, on reflection, that my hepatitis C had an educational effect on my children. They really did a lot for me around the house and things like that because of my ill health. It was kind of like they were my carers. I can't really say if this is entirely down to my hepatitis C or down to my GRO-B as well. One son returned to live at home when he was at uni, as I wasn't coping. My younger son did not leave home and helped with domestic chores.

28. I believe that my condition had an effect on my relationship with my GRO-B due to the fact that I was hiding my condition. I believe at the

time she could not have understood the distance I must have put between us though she is very supportive now. I believe with my sons this gave them more to worry about. I feel that as they only had one parent they were very protective of me. I don't doubt it affected them in many ways but they were also very supportive. They should have been freer to go focus on their own lives in their late teenage years instead of putting my needs first.

29. My condition had no effect on my mortgage as I got it pre-diagnosis and I have never had life insurance. I thought there would have been no chance of me getting it because I had hepatitis C. I know in my job I had a death in-service benefit. As I am now retired, this no longer applies.

30. I do get travel insurance if I travel but I do think that the premium is loaded. I only get it as and when I go on trips. I can’t get yearly cover. Usually I find that my travel insurance is double what it cost for my partner at least.

Section 6. Treatment/Care/Support

31. In terms of support I would say what was offered was not adequate. I did not go looking for help though because of the way I felt about my condition. I think if I had had support I may not have had such an issue with my condition. The nurses during my treatment were very helpful; I did think that to be supportive.

Section 7. Financial Assistance

32. I was not very aware of benefits around the time of when I was diagnosed. I knew there would be some benefits but I felt that it was a minefield to navigate everything on my own.

33. I received £20,000 from Skipton fund in 2004. I managed to apply for this myself. I did not know anyone else to talk about it.

34. I received £30,000 from the Scottish Government in 2016 and I believe that was an automatic follow-up. Generally I find financial assistance to be an easy process now and I can apply online.

35. I am now receiving money through the Scottish Infected Blood Support Scheme. This this was quite straightforward and I marked myself as severe. I only had my initial payment in the month prior to giving this statement. I remember feeling hopeful for the future a after my hepatitis C was cleared but the realisation my liver has been damaged and I will always have to have this monitored means I will never be free of Hepatitis C.

36. I am now receiving GRO-B per year which amounts to about GRO-B per month. What would have been great as if the government had just been honest and recommended financial aid earlier on; everyone's lives would have been better. It was then when I was trying to keep working and support my family that the financial aid would have helped most.

37. I received a winter fuel allowance from the Caxton fund previously. I didn't realise you had to apply every year.

Section 8. Other Issues

38. At the beginning of everything I never really thought of what had been going on behind the scenes in terms of making the decisions about contaminated blood. Everyone does make mistakes and at the beginning I was not judgemental but when I realised how much had been known at the time it made me quite cynical and angry.

39. I was not involved with the Penrose Inquiry, I believe that was because at that stage I was in denial. I was trying to be invisible at that time.

40. I wish for my statement to made anonymously.

Statement of Truth

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

Signed GRO-B

Dated 25/3/2019