Witness Name: Mrs GRO-B
Statement No.: WITN2144001
Exhibits: WITN2144002-008
Dated: 11th March 2019

# INFECTED BLOOD INQUIRY

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## FIRST WRITTEN STATEMENT OF GRO-B

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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 GRO-B 1942. My address is known to the Inquiry. I was married to GRO-B for 55 years. My husband passed away on GRO-B GRO-B 2019, we have two sons. GRO-B GRO-B I am retired and prior to retirement I worked as a GRO-B GRO-B GRO-B

## Section 2. How Infected

2. I received a blood transfusion on the 7th/8th December 1989 at Inverclyde Royal Hospital after surgery for a hysterectomy. I believe that two or three days post op, my blood levels dropped to a point where it became necessary for me to require a blood transfusion. I can't recall discussing the transfusion with the doctors, I believe they probably just gave it to me as a matter of routine.

3. The only blood transfusion I've had since then was during a hemicolectomy at the Royal Alexandra Hospital five years ago. I produce a copy of my medical notes regarding the hemicolectomy in evidence and refer to this as **WITN2144002.** Other than that first transfusion in 1989, this is the only other time I have needed a blood transfusion. I am now very wary of receiving blood to the point that I asked why they were putting a cannula in and asked them to stop when they were about to give me the transfusion five years ago. The consultant came and had a long conversation with me. One of the consultants treating me during my second blood transfusion was a Mr Vella. I believe it was a Mr McKirdy who ordered the transfusion. I did not know much about it but I know it was given to me overnight.

4. When I had my first transfusion in 1989 I was treated by a Dr George Anthony at Inverclyde Royal. During this first transfusion I believe that I received three units of blood.

5. Prior to my diagnosis having hepatitis C, I made frequent visits to my GP because I was not well. I knew something was wrong but did not know what it was. After some tests they said I had an underactive thyroid. I initially accepted this as a cause of me not feeling well. After a couple of years, my symptoms worsened and I had an itch that became unbearable. I believe my underactive thyroid was diagnosed in 2002 or 2003. They found that I had an underactive thyroid through

a blood test but they did not test for hepatitis C during this blood test. I was diagnosed as having hepatitis C in 2005. When I went to my GP prior to my diagnosis of an underactive thyroid, he told me that I had to have a liver function tests and thyroid test done in six months' time. I ended up initiating the test myself in early May of 2005. After these tests my GP called and referred me to Inverclyde Royal Hospital for a liver scan. I then had to go see a Prof. Jang Dilawari. It was Prof Dilawari who told me at the end of June 2005 that I tested positive for hepatitis C. I produce a copy from my medical notes relating to this and I refer to it as **WITN2144003**. I do not recall if he ever told me explicitly that they were testing for hepatitis C. I was not overly concerned about this as I just wanted to know what was wrong with me.

6. After a long discussion with Prof Dilawari, when my husband was present, I was asked if I ever had a blood transfusion. I said yes of course, and that it was back in 1989.

7. I believe that Prof. Dilawari did give me good advice. **GRO-B** **GRO-B** **GRO-B**. He said he would pass me to a good friend of his who he wanted me to be treated by. **GRO-B** **GRO-B** **GRO-B** **GRO-B**. I **GRO-B** **GRO-B** I did think at one stage about the fact that it can be spread by blood transfusion, but I did not make the connection between that and myself.

8. I do believe I was given adequate information by Prof. Dilawari and he did offer to help in terms of counselling and support. He said to call him whenever I needed to. I did find out more about hepatitis C through some communication I had with Roche Pharmaceuticals. I think the doctors I dealt with could not give me information any earlier than they did because they did not really know then. I believe that I should have

been diagnosed earlier than I was, given that I was diagnosed with my underactive thyroid in 2003.

9. In terms of cross infection I was told that we should not share toothbrushes and again I was given more information from Roche. I recall my husband had to be tested at our GP surgery and that test came back negative.

10. My husband and I went to the SIGN guidelines late in the year in 2005. The SIGN guidelines are the Scottish Intercollegiate Guidelines Network. I began to ask questions about my condition and how this was being dealt with. I remember because of the doctors responses to my questions, they said I was not a typical patient and gave some insight into the condition.

## Section 3. Other Infections

**11.** I was infected only with hepatitis C as far as I know. Although the treatment gave me auto immune hepatitis. I produce a copy from my medical notes that relates to this and refer to it as **WITN2144004.**

## Section 4. Consent

12. I do not believe there were any issues in terms of consent in relation to my treatment. At the time I was having tests done, I just wanted an answer as to why I felt the way I did. I think my GP obviously just did not think to have me tested for Hepatitis C originally. I went to see my GP **GRO-B** **GRO-B**.

## Section 5. Impact

13. I did suffer from flu like symptoms and had an uncontrollable itch all over my body. I produce a copy from my medical notes relating to this and refer to it as **WITN2144005.** The fatigue really was something else. That was one of the reasons why I retired at 60 although I had planned to work for longer. I did suffer a little from brain fog that led to a lack of focus and attention at times.

14. I did not suffer from any sickness and did not have a lack of appetite. I did find that sometimes at the weekend I would have a single drink and I would be unable to finish this.

15. I suffered from night sweats a tremendous amount. However, I would say that the symptoms of the treatment were far worse than just the symptoms of the condition.

16. As a result of interferon and ribavirin I now suffer from thyroid issues. I currently have to take thyroxine for this. I also have a heart condition called atrial fibrillation which has come up as a result of interferon and ribavirin. I have to take medication for this and it is monitored. This still affects my life beyond the treatment and I still have to take medication. Dr Mackay dealt with my atrial fibrillation. Dr Mackay was not convinced that my atrial fibrillation was brought on by Hepatitis C treatment but my own GP thought otherwise.

17. I was treated for my hepatitis with interferon and ribavirin. This was self-injected. Ribavirin was in tablet form. I injected on a weekly basis and took the pills two times a day. I produce a copy from my medical notes that relates to the treatment I received, I refer to it as **WITN2144006.**

18. I received treatment in 2005. It took a while to discover what genotype of hepatitis C I had. The genotype I have is 3A. I produce a note in my medical notes that relates to this and refer to it as **WITN2144007.**

19. In terms of injecting myself, there was a nurse at Inverclyde Royal hospital who told me what to do and she supervised while I tried it myself.

20. I did send away to Roche pharmaceuticals to find out more. They sent me a video of other people going through the same treatment as I was and showed how these people injected themselves. I recall that the professor treating me also asked for a copy of this video as it had been so helpful.

21. As I said, I did go to the Royal College of surgeons and physicians in Edinburgh for the meeting on the SIGN guidelines. When I heard that the guidelines for Hepatitis C were being updated I wanted to be involved. They waived the fee for going but I did have to pay for accommodation and travel to attend this. I believe this was on 3rd GRO-B 2005. People there were a mixture of doctors, nurses and patients. Most patients were prostitutes and drug addicts. During the Q&A session my husband got up and asked questions for me.

22. I do not believe there was any barrier or delay to my treatment. I think the only thing was the hospital did pay for it. They said either the hospital, my GP practice or I would have to pay for treatment. As far as I know the hospital paid for my treatment. This treatment was very hard to go through, but it was successful.

23. The treatment I had was for a period of six months. I was pretty much in my bed for the duration of treatment. It was dreadful and I was absolutely washed out. I injected on a Wednesday and then as I was approaching the next Wednesday I would start coming round then would have to be treated again so I would go back downhill. I lost a tremendous amount of weight and I would describe this treatment as being akin to chemo.

24. I suffered from total fatigue and suffered from terrible tremors and rigours. They said to use paracetamol when on the treatment but that really did not help. I went off food completely. I can't remember being physically sick but I do recall feeling nauseous and being sweaty. I cannot remember if the itch I had previously described got worse. I did have skin problems. The treatment has now given me autoimmune hepatitis. This was diagnosed after my treatment.

25. I was very low during my treatment and at one point I remember contacting a local hospice to see if they could help care for me but they said they only treated the terminally ill. They did offer to give aromatherapy and massage.

26. My social life was fully curtailed by my condition and treatment. I couldn't stay up at night and found I was in bed most of the time. My life was not the same during and even after treatment for a time. I had a very active social life before. We had a normal social life and didn't over-indulge in alcohol, we would go out for dinner and things like that. The symptoms of my treatment were devastating.

27. My treatment was successful but I do still suffer from muscle aches and fatigue. I have attended the hospital in relation to this. I was sent to the rheumatology department and given a medication that did not agree with me. Then in August 2006, Professor Dilawari brought up doing a liver biopsy and it was during this that I was found to have my autoimmune hepatitis. I do have fibrosis of the liver but I'm not cirrhotic as far as I know. I go to Gartnavel Hospital for this now because the two previous professors who treated me have retired. These were Prof. Dilawari and Prof. Peter Mill.

28. I was treated with steroids for my autoimmune hepatitis, which worked a treat. I was put on something called azathioprine. This produces weight gain and it's quite toxic. I am still on that now. I produce copy from my medical notes relating to this and refer to it as **WITN2144008**.

That was at the end of steroid treatment. I still have autoimmune hepatitis but the medication does help keep it under control.

29. My husband was an unpaid carer for me while I was on treatment. At one point I was so low that they were considering lowering my dosage. The nurses in hospital said they would make a rota to help me with my treatment. They did this on their own time and they were very supportive. I felt I had a good support network. The nurses were great and GRO-B GRO-B.

30. I do not feel like I was treated differently when going for medical treatment. I believe I would have noticed if they had. I think one of the biggest things generally is that people just don't understand. I think that it is only now that as things are very much on the news of late that people are much more understanding. I do not believe my condition had any impact on any dental treatment. When I have told any medical staff about my condition they have simply just said thank you for telling them. I recall one hygienist recently, when I mentioned I had cleared Hepatitis C, responded “so what?”

31. I believe the stigma has had a big impact on me. I didn’t worry about it coming up in conversation because I did not bring this on myself. I did feel that people lumped it in with HIV. I remember that one of the medical notes once had HIV on it in error.

32. I do not believe my condition had any impact on my children's education. I know they were very concerned about my health as well as the additional strain on their Father’s health. Both of them were out of the house at the time I was being treated. By the time I knew, I had grandchildren. I was initially worried about infecting other people, both sons had to carry on with life as normally as they could, they were also concerned about the possibility of cross infection. The shock played a big part.

33. In terms of the impact on my work I would say, as I have stated already, that I would have worked until I was 65. I ended up retiring [redacted]. I felt quite desperate at the time that I retired, as if my body was in a state of disrepair. I do not believe it really stifled my ambition though. This has had an impact on my pension and I have been left with a very small NHS pension. I think the hardest part was continuing with work when I fell ill.

34. My husband was retired due to ill-health at the time that I was undergoing treatment. During this time he became my carer (unpaid). When my husband was caring for me, I was unable to dress or wash myself, so I was very reliant on him. Two years ago I finally got attendance allowance at the middle range.

35. In terms of financial impact I would say that my husband and I were never ones to be spending a lot. Due to his ill-health retirement and my ongoing ill-health we had to be extremely careful with our finances. We got our travel insurance through the civil service, and as far as I recall you did not have to declare any pre-existing conditions on this.

36. [redacted]

37. I did have cancer of the bowel at one stage, but this has never been found to be linked.

## Section 6. Treatment/Care/Support

38. I would say that most of the information we learned in terms of support was found in what we got from Roche Pharmaceuticals. There was no real support offered otherwise.

## Section 7. Financial Assistance

39. I was disgusted at the fact that I have not been accepted for the benefit that is now called PIP. Two years ago, I recieved attendance allowance at the middle stage payment.

40. When it came to applying to the Scottish Infected Blood Support Scheme after listening to Prof Goldberg, I was of the opinion that I should put myself at the highest band in terms of how I have been affected. I went through my medical notes and found a letter saying that my auto immune hepatitis was possibly connected. I am worried about the effect of SIBSS payments on my attendance allowance, and I intend to speak with one of the infected blood or haemophilia groups about this. I marked myself as severe and I received £18,000 per year which amounts to £1,575 per month. This was backdated to September last year after I received the first payment in December. I think the biggest difficulty with this was the self-assessment. I would never have marked myself as high as I did without listening to Professor Goldberg. I am grateful to have listened to him. This was a very straightforward process and I had a long conversation with Professor Goldberg before and I said I was still having medical issues. So my condition is definitely severe.

41. From the Caxton Fund I did receive a winter fuel allowance of £500 on two occasions. When I realised that I had missed a number of years I checked to see if they would backdate this and they did not. It was an easy process to apply for these funds I found out about Caxton Fund when I was reading about the Skipton Fund. This mentioned Caxton and McFarlane.

42. From the Skipton fund I received £20,000 when I was diagnosed and then another £30,000 through the Scottish Government some years later. It may have been 2016 when I received the second payment. There is no monthly payment. It was an easy process and I believe it was Prof. Dilawari who told us about Skipton. I was surprised when I got the other £30,000 but it does not make up for what happened.

## Section 8. Other Issues

43. I did give a witness statement to the Penrose Inquiry but was not called to give evidence. I don't know that I would have wanted to. I feel the Penrose Inquiry was a complete waste of money. At one point my husband was speaking at the Scottish Government and met Andy Kerr who was then Health Minister. I believe that the Penrose Inquiry was a complete whitewash. It was a waste of public money. GRO-B GRO-B GRO-B.

44. I still feel the impact of my condition, I am still on medication and still have recurrent skin problems. It is still very much part of my life. It's sometimes difficult to get a consultant that is understanding.

## Statement of Truth

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

Signed GRO-B ______

Dated Jul 14, 2020