Witness Name: GRO-B
Statement No.: WITN2281001
Exhibits: none
Dated: 8th November 2018

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 8th 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 1965 and my home address is GRO-B. I am GRO-B: H wife. I intend to speak about my husband's experience of becoming infected with hepatitis C. In particular, the nature of if his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

2. H and I have been married for 32 years.

Section 2. How Affected

3. H was born with haemophilia B and contracted hepatitis C as a result of being given infected blood products.

4. H was born with moderate haemophilia B.

5. He received blood products in the 1980s that were blood-based. These products came from America and no one knew that they were infected until the early 90s. I do not remember the names of these products.

6. H received the infected blood products at the Royal Infirmary in Glasgow, I know one of the doctors who treated him was Professor Lowe.

7. My husband and I were told that he had received infected blood products in the early nineties but I don't know exactly when and wouldn't be able to indicate a particular timeframe. He was told that he was infected at the end of a routine medical appointment.

8. I think it is terrible that my husband was infected with hepatitis C and wonder why the blood that he received was never tested in order to prevent this from happening. My husband ended up getting a liver transplant. This liver transplant cured his haemophilia, but the hepatitis C will always re-infect the new liver. My husband is no longer a haemophiliac. The blood products from America were administered without being tested at all. Patients always assume that things are checked and those blood products were part of my husband's treatment.

9. No information was given beforehand about the risk of being exposed to infection as a result of receiving those blood products.

10. My husband did not receive any other infections such as HIV or Hepatitis B. He only received hepatitis C. He has been tested for HIV, and the test was negative.

11. My husband found out that he was infected with hepatitis C at the end of a routine appointment for his haemophilia, when a doctor made the following comment: *"by the way, just to let you know, you are infected with hepatitis C"*. I felt overwhelmed. I cannot

remember the name of the doctor who said that, he is not at the hospital anymore. Now, every three to six months, my husband has his blood checked at the hospital. At the time, he was also attending every 3 to 6 months. He did not get any of the symptoms for hepatitis C until years later. The symptoms probably started in 2009 or 2010. He was infected in the 90s but I do not know when.

12. When first told about the infection, we were just told about the fatigue that my husband might experience and that a scan of the liver would be necessary. The doctor knew that we had not previously known about the infection and that it was the first time we ever heard about hepatitis C.

13. I don't think that adequate information was provided to understand and manage the infection. Later on, the symptoms started coming. These were fatigue, yellow eyes, ache all-over and flu-like symptoms. My husband had 2 treatments for hepatitis C at the Glasgow Royal Infirmary, both failed. Then he had a liver transplant six years ago, and 2 more treatments after that. The first of his last two treatments failed as well. The final treatment started on August 6th 2018 and finished on 20th January 2019, after this treatment, my husband was tested on 23rd January 2019 and so far the virus has not been detected. It was only shortly before his first treatment that my husband received information on lifestyle and on how to manage hepatitis C. It was not until he had already started showing symptoms that he received this information.

14. I believe that information should have been provided earlier, instead of waiting until the hepatitis C symptoms were already present.

15. My personal view is also that there should have been a specific appointment to tell us about the hepatitis C and what would or might happen in the future rather than making the announcement that my husband had hepatitis C at the end of a routine appointment. I felt that the way in which it was communicated to us was quite poor and I thought to myself: "*oh no, this is something else to be in hospital about!*"

16. We were not given any information about the risks of others being infected as a result of the infection. I have never been tested for hepatitis C and I am not allowed to give blood.

The reason why I am not allowed to give blood is because my partner is infected and I had to explain this to the Blood Transfusion Services when they came to my workplace. I have never given blood.

Section 3. Other Infections

17. I do not believe that my husband received any infection or infections other than hepatitis C as a result of being given infected blood products. We have never been told that there was a chance that he might be infected with anything else other than hepatitis C.

Section 4. Consent

18. I do not know whether my husband was ever treated or tested without his knowledge or without his consent, or without being given adequate or full information. The point that I would like to make is that H always attended hospital to receive treatment for his haemophilia and that every time that he received a blood-based treatment, that was the only option that he had. We are not aware of him having been treated or tested for the purposes of research. I should point out that the first treatment that he got for his hepatitis C was a drug trial, but apart from that I would not say that he has ever been treated or tested for research, at least not that we are aware of.

Section 5. Impact

19. H being infected with hepatitis C had a huge impact on our family.

20. When our children were younger, there were times when he wouldn't get out of bed or and couldn't do anything. On such occasions, I had the children stay with my mum and dad for a while because I did not want them to see the state that their father was in. My husband has always been quite an upbeat person. When the hepatitis C symptoms appeared, he used to not to able to get out of bed for maybe a week at a time. Mentally, he was constantly down and depressed. He told me that I could leave him if wanted to, because it wasn't fair on me. He experienced tiredness. At some point, he needed hip replacements and could not get them due to having hepatitis C. He had already had 2 hip replacements in the past

at that point, but Glasgow Royal Infirmary referred him to Edinburgh Royal Infirmary for his third one due to the liver transplant. He eventually had a hip replacement at Edinburgh Royal Infirmary earlier this year and it was long overdue.

21. His general health went downhill as a result of contracting hepatitis C and eventually he got put on the waiting list for a liver transplant, which he had on April 1st 2011. The transplant was straightforward and he had been on the waiting list for a year when he got it. After a year, however, the new liver started showing traces of hepatitis C.

22. The course of his illness was that his health deteriorated and it was more about the tiredness than anything else. By the time he got put on the waiting list for a liver transplant, he could not walk far and he couldn't do anything really, because he could not go further than 1 hour away from the house. The reason why he could not go further than 1 hour away from the house is that you would need to be close as they could call you about things being ready for the transplant to take place at any time. We felt like our life was put on hold for a year. The hepatitis C then re-infected the new liver and we were told that he is only allowed one more liver transplant, and no more after that. However, this was 6 years ago. I do not know whether the policy will have changed and whether or not my husband would be allowed more liver transplants if required.

23. My husband has had five treatments for his hepatitis C, three of which have failed. He has just finished his fifth course of treatment, which he will completed in January The first two treatments that he had were Interferon and they made him really sick. However, they failed. After the first treatment he was cleared for three months and then the hepatitis C reappeared. He is now on his fourth treatment and appears to be cleared of hepatitis C, but we don't want to celebrate it because the hepatitis C might still reappear and we have been there before. He has just finished his fifth treatment which was a six-month treatment and was the longest he had ever been on. I do not remember how long the other treatments lasted. The third treatment might have lasted three months. His fourth treatment is simply tablets that he takes at home and he has to go for blood tests every four weeks.

24. When the third treatment failed, I asked where we could go from there. I was told that a fourth treatment wouldn't be feasible because of the amount of money these treatments

cost. This was an obstacle to access to treatment. My husband started to experience more fatigue. We had to keep attending doctor appointments. Finally, he was given his fourth treatment. We are concerned that if this treatment fails, he will not be offered any more. It was the doctors who referred him for the four treatment, but Glasgow Royal Infirmary and Edinburgh Royal Infirmary had to agree on this because the cost is high.

25. There were no treatments which ought to have been made available but were not, at least not that we know of.

26. The first and second failed treatments which he received caused my husband's mood to change and he became a very different person. He was not very nice to live with throughout the duration of any of his treatments. He was very sick during his first two treatments, especially the first one. He did not lose his hair, but he did lose his teeth and was always vomiting and had to stay in bed, particularly with the first one. My husband was meant to go for another hip operation last September, but the doctors detected a problem with his heart that he has never had before. For this reason, he could not go ahead with operation. Glasgow Royal Infirmary have denied that the heart problem has anything to do with his hepatitis C drugs. However, they do not want to treat his heart condition until the treatment for his hepatitis C is clear so that there are no interferences. The treatments have made us feel very emotional because when they don't work, then you are back to square one all over again, hoping that they will work this time around.

27. I would say that my husband's infected status has impacted upon his medical treatment. The reason why I say this is that he needs treatment for his heart that he is not able to receive because of his hepatitis C and the hepatitis C treatment that he is on just now. It is a vicious circle. My husband used to always go to Glasgow Royal Infirmary for his dental treatment. However, even though my husband has had so many operations, he is still terrified of the dentist. He has lost his teeth due to all the treatments for hepatitis C that he has been on over the years, but he is too afraid to go to the dentist. He always says that when his treatment is finished, he will go to the dentist and get it sorted.

28. H becoming infected with hepatitis C has had a huge impact on our private, family and social life. We don't have much of a social life and, if we go out at all, we are always

first to leave because H gets tired. It has totally changed our lives and some friends just don't understand this because it's been going on for so long and this is our life now. We have lost friends because of the infection. Both our families are good, but everyone works and everyone is busy, so no one pops in to see how H is doing. We used to send our children to their grandparents' a lot when H was very sick, and we kept a lot from them in order to protect them because they were just children. Our daughter is thirty years old and she is married now, so she doesn't live with us. Our son is 26 years old and he sometimes stays with his girlfriend, so we only see him now and again. We look after our granddaughter on a Thursday afternoon and on a Friday. It is only me who can take her out as my husband cannot run about with her, he can only watch films with her. She has become used to this situation.

29. I think that there is definitely a stigma associated with a diagnosis of hepatitis C. Years ago, I used to be a child carer here at home and one of the treatments my husband had at the time was injections. I let parents know that the injections that my husband used were in the fridge, and even though the fridge had a lock so that the children couldn't open it, on parent removed their child from my care despite there being no risk. Many people felt like they could catch hepatitis C by simply using the same towels or soap as an infected person. A lot of people just assume that hepatitis C is either drink related or drugs related and I feel like I have to explain my life story and how my husband contracted hepatitis C to avoid being judged, when I really shouldn't have to.

30. My husband had to give up work at age 48. We were hoping to retire early, but not as early as that. He worked as a building manager. He has been unable to work ever since. He was struggling more and more at work and eventually had to stop. He worked for his brother, and his brother could see what was happening. I still worked full time for a few years after my husband had to give up work, but I was struggling too, so I became part-time. Now I only work 3 days a week as I need a lot of time for hospital appointments. H could not drive to these hospital appointments because he suffers from poor concentration and forgetfulness, which are side-effects from his hepatitis C. However, he always says that he is fine, even when he is not. He says this so as not to become a source of worry for people.

Section 6. Treatment/Care/Support

31. I do not think that care, support or counselling were ever offered to us as a result of H contracting hepatitis C.

32. I have been to a counsellor once already because I suffer from depression. I am now on the waiting list to go see a counsellor again. H and I are also members of support groups for people who are awaiting or have already had a liver transplant, but I couldn't cope with attending these group meetings. The reason why I could not cope is that I found these meetings to be counter-productive because they were depressing, or at least more depressing than they were beneficial. These meeting were depressing because people who had already had the liver transplants would discuss all the health problems that happened to them afterwards and this made me very worried about what might happen after my husband's liver transplant. I do not know if the group meetings are still ongoing, but they could well be as long as people are still voluntarily attending. I obtained counselling through the NHS because I requested counselling myself, it was never offered by the doctors dealing with H hepatitis C infection.

Section 7. Financial Assistance

33. We received financial assistance from the Skipton Fund.

34. I cannot remember when we found out that financial assistance was available, but I think that we found out about it from the Royal Infirmary in Glasgow.

35. H received two lump sum payments of £20,000 and £25,000. Now he receives monthly payments of £2,250 per month. All payments came from the Skipton fund, but we received lump sum payments a long while ago, I cannot remember when. At first, H was considered Stage 1 for the payments and though he applied to be stage 2, his bloods were not bad enough to be granted this. However, as soon as he was on the waiting list for his transplant, this changed and he was automatically granted stage 2. He was given

the two payments of £25,000 and received a monthly payment of £1,250. When SIBSS took over from the Skipton fund, the amount that H received increased from £15,000 to £27,000 per annum. This started in April 2017 but was backdated so H received a further lump sum of about £12,000 due to back dated payments.

36. The process of applying for financial assistance simply meant that we had to fill in forms and post them out.

37. We had no difficulties or obstacles when applying for and obtaining financial assistance, it was quite a straightforward process.

38. There are different criteria that you have to meet in order to qualify for financial assistance, and you have to disclose all the medication that you have ever received and when you became infected.

39. We have received a fair amount of money, but H has not been working for a long time and we don't know whether he will ever work again, he is always in the house now and no amount of money is ever going to bring back his health. However, I think it would have been fair to receive at least the amount of money that H would have earned if he had been able to continue working if he had never become infected. I cannot put a price on health, but I will say that coping with the illness is bad enough and that our lives have totally changed. H money went up last year and for that reason he is now getting £2,250 per month rather than simply £2,000.

40. I have not personally received any financial assistance. It used to scare and worry me that if H died his entitlement would die with him. However, this changed last year. If H died now, I would be entitled to three fourth parts of his monthly income. These payments are not coming from Skipton anymore, but from the Scottish Branch. I think it is called NSS, which stands for National Service for Scotland and runs through the SIBSS, which stands for Scottish Infected Support Scheme. This is all run through the National Health Service.

Section 8. Other Issues

41. We have been involved in the Penrose Inquiry in the past. We have not been involved in any court proceedings as a result of H becoming infected with hepatitis C and we have not been involved in any campaigning either. We have not been involved in any other investigations.

42. There are no specific documents that come to mind that might be relevant for the purposes of the Inquiry.

Statement of Truth

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

Signed ____ GRO-B

Dated ______ 14/02/19.