Witness Name: GRO-B
Statement No.: WITN4489001
Exhibits: none
Dated: 15th October 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 15th May 2020.

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

Section 1. Introduction

1. My name is GRO-B. My maiden name is GRO-B. My date of birth is the GRO-B 1962 and my address is known to the Inquiry. I have been married to my husband GRO-B: H GRO-B GRO-B GRO-B I intend to speak about my husband H GRO-B who was born on the GRO-B 1954 and who contracted hepatitis C after receiving a blood transfusion in 1988. I will speak in particular about the nature of his illness, how the illness affected him, the treatment he received and the impact it had on his and our lives together as a family.

2. I wish to remain anonymous for this statement.

Section 2. How Affected

3. H has always been really easy going, he has a fantastic personality. Everybody always says that they broke the mould when they made him. He has always had a good nature to him and always takes good care of himself. He doesn't really drink and he's never smoked and he has never been overweight. He is a wonderful Dad and a great husband. H works for GRO-B GRO-B He has been in that position for around twenty years. The infection has had a terrible impact on his life, it has changed him in so many ways. It has put him through a lot of things in life that he didn't need to go through.

4. In 1988, I cannot remember the exact date, H came home from work one night and collapsed whilst he was in the bathroom. He was rushed to Ninewells Hospital, Dundee where it was discovered that he had a perforated ulcer. I cannot remember exactly what treatment was required but as result of the perforation, H had lost a lot of blood and required a blood transfusion. H contracted hepatitis C as result of that blood transfusion.

5. H did not receive any information about the risk of infection posed by receiving the blood transfusion. That kind of thing was unheard of then.

6. H was diagnosed around nineteen years ago, I cannot remember the exact date. I received a phone call at home from the Blood Transfusion Service. The SNBTS had been to H work to collect blood donations and H had donated blood. They asked if H was home and I said he wasn't but asked if there was anything I could help them with. They said, "*Could you pass the message on to your husband that he has hepatitis C*". I had no idea what the infection was at that time, so I asked what it was. The man said it was blood borne virus and it meant that H wouldn't be able to give blood again. The man said they would send out a letter and arrange an appointment to see him. I called H at work and his boss let him come home. We were

both very upset when we started looking into the infection and realised what it could lead to.

7. Following that phone call we did receive a letter to arrange an appointment. I know that H went in for an appointment at the Glasgow Royal Infirmary but I cannot remember what was discussed when he went in. I cannot remember the exact date of this appointment but it would have been a week or two after the phone call from the SNBTS. He had the infection explained to him a bit more and was given some information about hepatitis C, but I cannot say exactly what was said to him.

Section 3. Other Infections

8. H has not contracted any other infection other than hepatitis C as far as I am aware.

Section 4. Consent

9. I do not believe H has ever been treated or tested without his knowledge or consent.

10. I do not believe H has ever been treated or tested for the purposes of research.

Section 5. Impact

11. Mentally, when H was first diagnosed, he had a lot of paranoia about infecting myself and our children. He was always worried that we would catch the infection somehow. There was a lot stress involved in making the kids aware of what was going on making sure they knew about how to be careful with things like toothbrushes or cuts they might get. One of the biggest worries we both had was that our youngest son, GRO-B, might have the infection because he had been conceived whilst H was infected. We were so scared for years about having him tested, in case he had to go through the same things that H had gone through physically and mentally. Luckily, we

found out through blood tests GRO-B that he did not have the infection. The worry from the possibility that GRO-B could be infected caused H a lot of stress though.

12. I know H felt embarrassed about the infection as well, that was something he and I both dealt with for years. We told the children that H had received bad blood and that was why they had to be so careful but we also told them not to tell anyone about it. The stigma surrounding hepatitis C was what caused a great deal of that embarrassment for us both, it wasn't something you could really tell people without them passing judgement. It was something that people associated with drug addicts and we wanted to distance ourselves from that association. H GRO-B the stigma had such a big impact on us.

13. The infection also caused H to have mood swings form time to time and he would often have issues with his concentration.

14. Physically, the infection brought on aches and pains in H joints. Those aches and pains would be a constant thing he had to deal with. He also suffered from a great deal of fatigue that still persists even now, he has to sleep constantly. There are times when he comes back from work and as soon as he sits down, he falls asleep.

15. I cannot say for sure whether H infection led to any further medical complications or conditions.

16. H first treatment was a course of Interferon and Ribavirin though the Glasgow Royal Infirmary. I cannot remember exactly when he began that treatment or how long the treatment itself was. After he had completed the treatment we were told that it had been unsuccessful. That news was devastating for us both because of how much it had put H through, the side effects were absolutely horrific.

17. H had a second treatment a few years ago that was successful. This treatment was also through the Glasgow Royal Infirmary but I cannot

remember what it was called or how long the treatment was. I think there was a gap of around two years between H first and second treatments. I remember the treatment being described to us as one with a very high success rate. After he had completed the treatment he was tested and it was shown he had cleared the virus.

18. H did not have any issues in accessing either of his treatments.

19. I do not believe there were any other treatments that could have been made available to H that he was not offered.

20. H first treatment with Interferon and Ribavirin was terrible for him. He would suffer from really bad fatigue, almost all the time. The fatigue that he already dealt with just got so much worse. The aches and pains in his joints seemed to get worse when he began treatment as well. The treatment also caused brain fog for H which greatly affected his ability to think and concentration.

21. That first treatment had quite a serious effect on his mental health. He would have very regular mood swings and he suffered from depression quite often. Those problems also created a lot of stress for H, on top of having to push through the infection and the treatment. I think he was aware of the change in himself and that was very difficult for him.

22. Throughout H first treatment, he suffered from an underactive thyroid and that caused a lot of his fatigue. I believe his treatment caused the problems with his thyroid. He still requires medication to treat the underactive thyroid the treatment caused and takes Levothyroxine daily to treat it.

23. H second treatment did not cause as many problems as Interferon and Ribavirin. There was some stress and worry about whether it work but there were not any severe side effects like this first round of treatment.

24. During the time H still had the infection, he would sometimes have to tell dentists or doctors about his infection so they could take the necessary

precautions. H found it really embarrassing having to tell people about his hepatitis C. I remember there was a time when H was in hospital for something and there was big sticker on the front of his chart that said he had hepatitis C. It was just there for everyone to see and that was very embarrassing for him. He would say sometimes that he felt the doctors or dentists would almost look down on him after he told them about his infection. They couldn't have known that he contracted the infection through infected blood but that doesn't justify their attitude.

25. For me, the infection had a huge impact on our family life. My husband went through so much mentally and physically, it was really hard to watch. Our social life really suffered because H wouldn't be able to drink alcohol without getting really unwell and that limited the kind of things we could do. The infection made it extremely difficult, if not impossible, to get health or travel insurance and that meant arranging holidays became a huge stress. Sometimes I would have to go on holiday GRO-B because it was so difficult for H to get the insurance he needed to go abroad.

26. Our children seemed to have coped okay with H infection. I have asked them about it and they say they can remember how unwell he was and how often he had to go to the hospital and things like that. I think they've processed everything okay but part of that was because we shielded them from a lot during H infection. The way the infection impacted them was how careful they had to be with cross infection when they were growing up. They always knew they had to have separate towels and separate toothbrushes for example but we didn't tell them that was because H had a potentially life threatening virus.

27. Before H received treatment, his infection meant that he often had to take days off work because of the fatigue. He would sometimes just need the days off to recover physically. What made that difficult was that H didn't want to tell his work about the infection for the fear of the stigma. That meant that when he needed a day off he would often take that day as annual leave instead

of a sick day so he didn't have to keep making excuses. That time off did have an effect financially, he wasn't off that often but those were days he was unable to work a full day.

28. H had to take a lot of days off work during his first treatment. Some of those days were sick days but he had to use a lot of his annual leave as well. He used the annual leave because again, he didn't want his work to know that he had hepatitis C. The amount of annual leave he had to use meant that we didn't go on holiday during that time because he barely had any days of annual leave left. When the annual leave days had been used, he had use sick days and that meant he was only receiving SSP which was quite a strain financially.

29. We were lucky enough that when H did have to rely on SSP, I was still in fulltime employment so that covered some of the shortfall. It was still quite a strain losing that income though.

30. We had some real problems with our mortgage because of H infection. We already had a mortgage in place when H was diagnosed with hepatitis C. We decided not to tell our mortgage provider that H had hepatitis C and that was very scary for us because of the uncertainty it created. We were just scared to tell them in case we lost the house because our mortgage was based on his salary, we just didn't want to take the chance.

31. We had an endowment mortgage with a shortfall of £30,000. Having to pay that mortgage with the constant worry of something happening to H was horrific. The worry that H could die and leave me with GRO-B children and our mortgage to pay, with our provider not knowing about his infection, had a huge effect on H mental health. Luckily enough, H and I were able to pay off the mortgage around seven years ago but we still had the shortfall of £30,000. We went to our provider to take out a mortgage for the remaining £30,000 and it was at that point that we decided to tell them that H had hepatitis C. The women we spoke to said that because of H infection, we would not be able get a mortgage for the shortfall, despite having consistently paid or mortgage for twenty eight years. The women said one

solution would be to take out a loan for the remaining £30,000 in both our names but only I would be insured on the loan. We walked out of that appointment enraged, we had paid or mortgage all these years and we thought that part of our lives was over. H actually burst into tears, he couldn't believe it. We ended up taking the loan and paid it off in January of this year but it was extremely stressful. I was very lucky to be in fulltime employment, I don't know what we would have done otherwise. If anything had happened to H in that time, the loan would not have been paid off as his infected status meant he wasn't able to be insured. If anything had happened to me, it would have been, because I was able to be insured for the loan. Those sort of situations are unacceptable. The lenders do not care about the circumstances of how someone contacted the virus. It didn't matter that H had been in fulltime employment his whole life, they weren't interested. H infection meant his financial status didn't count for anything.

Section 6. Treatment, Care and Support

32. H did not face any difficulties in accessing treatment, care or support because of his infection.

33. H has never been offered any form of psychological support or counselling because of his infection. I think he definitely would have benefitted from those if they had been offered. It would have helped him deal with a great deal of the stress and mental health issues that his infection has caused over the years.

Section 7. Financial Assistance

34. H received £20,000 from the Skipton Fund many years ago but I cannot remember exactly when. I cannot say for certain how H found out about the Skipton Fund. He does a lot of reading and research around infected blood so he could have found out through his own research but I couldn't say for sure. H completed the application for the Skipton Fund on his own so I wouldn't be able to comment on the application process.

35. H also receives a monthly payment from the SIBSS and those payments began around two years ago. I do not know how much he receives from those monthly payments, they just go into our joint account and they go on our outgoings. I cannot remember how we found out about SIBSS. Again, H completed the application for SIBSS so I wouldn't be able to comment on the application process.

36. I would say that I don't think either of the funds were particularly well advertised. I had never seen them anywhere before and if H hadn't been doing his own digging, we might not have ever come across them.

Section 8. Other Issues

37. One issue that we have had difficulties with over the years, is getting insurance, of any kind, because of H infection. Health insurance, life insurance, travel insurance, you hit brick walls everywhere you go. I think it's disgusting that insurance companies can leave people like H in limbo. H hasn't been able to get life insurance since his diagnosis and that means there is so much worry about what would happen if H died. It leaves us in a horrible position. Even now that he has cleared the virus, insurance companies don't want to touch the situation, it's terrible. We have to make sure that we have money saved in case anything should happen and that's our only option. Not being able to get travel insurance is a huge problem as well. It means that we've not been able to go on holiday as family because we would be putting so much at risk going abroad without H being properly insured. If anything happened to H abroad we could end up paying thousands of pounds. It feels like we are being constantly penalised for H health. As a family we have missed out on a lot happy memories because of how difficult insurance is to get.

Statement of Truth

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

Signed GRO-B ______

Dated Oct 15, 2020