Witness Name: GRO-B
GRO-B
Statement No.: WITN2253001
Exhibits:None
Dated: 4th January 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 the 5th November 2018.

I, GRO-B, will say as follows:

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B 1959. My address is known to the Inquiry. I am currently working full time as an GRO-B and I am married to my husband GRO-B I intend to speak about my infection of hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact on had on my family and I and our lives together. Please note that I wish this statement to be anonymous.

Section 2. How Infected

2. I received a blood transfusion on the GRO-B 1985. I was pregnant and I went into early labour. I had problems throughout the pregnancy and at 26 weeks I went into spontaneous early delivery. The upshot of this is, that I lost the child. His name was GRO-B I was haemorrhaging from the word go and after GRO-B was born he was taken away; I was taken into another room where I was given a blood transfusion over a period of a few hours. I remember that the nurse came in at one point and changed the blood bags over and I took a severe reaction. I started shaking and I remember thinking I was going to die. There was a lot of nurses and doctors around me and they took me off the blood at this point. I can't remember anything else up until when I woke up in a side ward the next morning. This was at Dunfermline Maternity Hospital which is now no longer in existence. I don't know any names of the consultants and I don't know how many pints of blood I received. Nobody explained anything to me, I was probably not in a state that I could understand anything. As far as I know, no explanation about the risk of receiving a blood transfusion was ever discussed and nothing was put on my discharge sheet to my GP about me having even had a blood transfusion. So my GP was not even made aware. I discharged myself on the GRO-B I signed myself out, against doctor advice. No follow up treatment was ever given and there was no information.

3. In 2010, my husband GRO-B had gone to the doctor as he was unwell. They were testing him for various things and advised that I should be tested as well. I had my blood tested and I was then told that I had hepatitis C. I was shocked because I had not had a clue about this, I did not even know what hepatitis C was. I went to see a doctor at Victoria Hospital, Kirkcaldy, where I was accused of being a junkie. The doctor repeatedly asked me when my next fix was and when was my last fix. He was convinced that I was a drug addict. I remember leaving that appointment absolutely traumatised and distressed. I had kept reasonable health between 1985 and 2010, I had had

a few mystery illnesses that were never solved, however I was mainly well. I remember I lived up North at one point in 2007 and I had pain where my liver was. There were investigations done at Raigmore Hospital, Inverness, including a scan and a CAT scan but nothing came from that. Eventually the pain went away, but I was in agony for quite a long time. I also remember I started suffering migraines when I was 26 years old, just after I lost GRO-B I still suffer with these migraines to this day; there is no medical explanation for it, I've tried keeping diaries and all sorts of things and I have tried various remedies. I have even been on epilepsy treatment at one point, to no avail.

4. No advice at all. I didn't go back to the hospital or the GP after I was diagnosed. I was in a state of denial; I was not going to be treated by anyone in the way that that doctor at Victoria Hospital treated me. My confidence took a hell of a knock that day so there was no information about the infection.

5. The information was not adequate, it was accusatory. They just wanted to tell me I was a junkie. I did not know anything about infected blood, I had to look up hepatitis C myself. I was gutted that I was treated this way. Ultimately it would put anyone off being accused of something that was not accurate.

6. I believe there should have been adequate information when I received the blood transfusion in 1985 as there was a possibility about infection. I understand the reason why there was no discussion, there was a lack of knowledge at the time. I was also weak and I had lost a lot of blood but at that point there should have been a discussion about the risk involved, even with GRO-B I don't understand why they couldn't tell me at the time and certainly a lot more practical information after the diagnosis.

7. The information was poor; the way it was communicated was poor.

8. No, there was no discussion about the risk when I was diagnosed.

Section 3. Other Infections

9. There has never been any discussion about being exposed to anything else other than hepatitis C.

Section 4. Consent

10. I was tested for a mystery illness without them telling me the possible outcomes. There was no mention that it could be anything to do with my liver in 2007 and I did not know I was being tested for hepatitis C in 2010. I find the liver pain strange and I have not reviewed my medical records that are recovered as there are so many of them and some of the records are missing now.

11. I believe that I have been tested without my consent as above.

12. I recovered the records in 2015 for the Skipton Fund. I had to prove I had a blood transfusion which meant I had to run around everywhere, hospitals, health boards, the blood transfusion service and doctors to get this information. The information was not accurately recorded all together and there was a lot of records missing. They made the process very difficult. After my diagnosis in 2010 and the treatment in the hospital in Kirkcaldy, I have undergone treatment and I am now considered non detectable. This doesn't mean I have not got hepatitis C anymore; it just means that they cannot see it. I feel like I still have the infection, I still have problems now. So the information is not full and adequate.

13. .I believe, yes it is possible I have been used for research. I have been tested for the effects of hepatitis C looking at what I can gather from my records. Hepatitis C doesn't manifest itself for a long time, there have been a lot of blood tests over the years. They wouldn't have tested for that virus automatically but they probably should have. They possibly knew that I had hepatitis C because of the blood transfusion and left me alone hoping that I didn't figure this out as I didn't show any symptoms, this is also a possibility.

Section 5. Impact

14. Mentally I am not in a good place. My head doesn't believe that I am well given that I didn't know I was ill for 30 years. There was a big emotional impact from having to run about and having to find all the information required to prove that I had had a blood transfusion for Skipton, it took a lot of effort, a lot of disbelieving people. Even after the treatment there was a lot of people who believe that I was a junkie for many years and this is extremely upsetting and affects me to this day. I think the main physical symptoms that I have experienced however, have come from the treatment and not from the hepatitis C itself as it lay dormant in my system for many years.

15. I feel the hepatitis C is still there, I feel it is still in my body is how I would express this, the doctors have never given me any follow-up or any tests to see if this has ever returned. After the treatment they just told me I was fine and discharged me, this has left me in an emotional hole.

16. I went on interferon and ribavirin in 2015. I went on the treatment for 4 months and 3 months later I was declared undetectable. The treatment itself was hell of earth. My hair fell out, I had massive sores and scabs on my head, down my neck, around my eyes and pain like I've never had pain before. During the treatment, the clinical nurse was going to stop it because I was having such a severe reaction, but I decided I was halfway through the treatment and I would keep going until the end to get rid of it. They offered to stop the treatment and retake it at a later date but I decided against it. I still suffer everyday now as a result. I have pain in all my joints, ankles, feet, knees, hips, shoulders, arms, these are severe pains and I am constantly taking pain medication. I have developed arthritis in my hands and I don't trust doctors anymore so I don't go to the doctor unless it is absolutely necessary. Because of the pain I am in, it would have to be extraordinary. I won't let a hospital near me otherwise, I have to be unconscious. I am constantly tired but I have no official diagnosis of chronic fatigue. I am not diagnosed with depression, because I won't go near the

doctor. I wouldn't trust anyone in the medical profession anymore, this has been done to me. Last time I was at a doctor it was for a cervical cancer screening, that is the only time I would go, if cancer was involved. I sought treatment in 2015 for hepatitis C because I had looked on the internet about what it would involve. I couldn't be near my grandchildren for fear of spreading the infection. I saw the new treatment so I asked to be referred, I read online that this treatment only took a matter of months and I wanted to have a life with my grandchildren. I wanted to tend to their grazes and help them when they fell and hurt themselves. I had this horrible fear that I might infect them so I stayed away, every time they needed me. The eldest grandchild is now GRO-B

17. There was a huge waiting list for treatment. Other difficulties were getting to the hospital, it was Dunfermline or Kirkcaldy, if I didn't have H I would not have coped. He took me every week, he even offered to inject me, every week with the treatment, but I had to get over that and do it myself. I found it very hard injecting myself, even giving blood at the doctors, I panic. I have never liked this. That 5-year period from diagnosis to starting the treatment, the only thing the doctors were interested in was if I was a junkie. I can't stand needles. The treatment was an epi-pen that you inject into your stomach, which was horrible. I didn't get over that. I had to do it though, I still don't like giving blood, I look away when it's happening, I don't know how I got through that whole period.

18. I don't know, this was the treatment for my particular genotype. I don't know what genotype I am so I don't know if there were other treatments available.

19. My troubles have just continued, the only thing that is better now is that I can cuddle my grandchildren but then I think the virus is still there. I feel the same now as when I was going through the treatment. I feel like things are running through my hands and feet, it is the only way I can describe it. I have never been tested formally since then and I have never been formally released from the hospital to my awareness. They just said it was non-detectable. I think I would have appreciated follow up appointments to check

and see how things were going, but now I would refuse any further appointments. They didn't care. I don't blame the staff or anything like that, they are just doing their job. When the staff did the transfusion originally, they were also just doing their job as well, I might have died without it.

20. Unless I am dying, I won't go to the doctors. I went once after the treatment to see about the pains in my hands and the pains I was getting. It was dismissed and I was sent out the door and told to get on with it. They have no interest. I did say to them at the time that the pains in my hands had only developed since the treatment and it was not getting any better, it has been getting worse over the years. At one point I was sent to a hospital for an x-ray but there was nothing found; it was inconclusive. I didn't go to the dentist for a long time after my diagnosis. I stopped going when I went up North and the only time I have been to the dentist since then is when the plate in my mouth broke and I had to have it repaired. I went to the dentist who did this because I was self-conscious about my mouth. I also have this fear of the stigma because I have to tell the medical professionals about my infection. If I go on holiday, I can't get holiday insurance because of the hepatitis C. If I declared I had this or I was previously infected, insurance wouldn't pay out if anything happened to me because I didn't declare it, so I don't bother. I don't have life insurance, I have life insurance at work, however there is not a lot of people who know about my infection, including the insurer. I had to tell my immediate colleagues at work at the time because I was off and getting treatment and I didn't know what the impact would be. I did tell some colleagues and they were fine but not the organisation. Nobody in senior management knows about it though. I have seen their reactions of them towards others who have medical difficulties. They judge them and decide that they are unfortunates, no good etc. No way I was going to tell them about my infection. I refuse to go to the dentist otherwise. The other thing is that I still have to declare it even though its undetectable, it proves to me that hepatitis C is still considered to be a drug addict disease and that is the feeling I get, if ever I was to say to anyone I had hepatitis C. During the treatment, I thought I would be given more

information than I was about the effects. I didn't realise how much the interferon treatment would affect me, I was told it would be flu like symptoms; even to this day I suffer everyday physically. It's been since the treatment more than the hepatitis C, that these symptoms continue. I did work full time during the treatment, it was to keep my sanity mainly. I don't really have a social life now, before I was diagnosed I was considered a social butterfly, I had lots of nights out, however that just does not happen these days. I don't have a sex life. I have a supportive husband but this is just not something I am able to do. Even though I am clear or undetectable, I still feel infected. I have a fear about spreading this and ending up infecting GRO-

21. I have always done my own medical things because I am allergic to plasters. A normal first aider would just slap a plaster on any cut, so I just treat myself. I did tell one other colleague about the hepatitis C in confidence. They spread it around and repeated it to others who then shunned me. The reaction from them was awful. It is the look in their eyes, they immediately think 'Junkie'. I certainly wouldn't tell anyone now unless I was forced. This stigma doesn't go away. Doctors think this is how I was infected so what chance does someone on the street have that has no medical training. Some colleagues have been supportive, but others were just nasty people. I have never spoken with them since then, I just stopped. I found out that it had been spread around because one person said to me "*I hope you get better soon*", obviously at the time they could see something was wrong because I was going through treatment at the time and I looked dreadful. I asked her how it was she knew I was infected and she then told me that it had been spread around and there was a huge group of people that knew. This group of people stopped speaking with me, they wouldn't speak to me, they would just walk away from me in the kitchen when I was making tea. I have no involvement with them now. The management that I did tell about the infection, were very supportive of me. When I was going through treatment they acted appropriately, however I am scared of the reaction of other people now, knowing what the reactions have been previously. I am working in an office in a room on my own now, I keep away from the

mainstream with the rest GRO-B but I don't believe that this is anything to do with being infected.

22. I didn't take a financial hit because I worked all the way through treatment. The only time I stopped working was in the last few weeks of treatment because I had a lot of time off for hospital appointments and things and they were very supportive and let me go home early. I don't know what would have happened if I had stopped working. With hindsight, it would have helped if there had been an option to stop going to work, a sabbatical of some kind, to allow me to recover. I should have had the option and would have appreciated proper support with this.

23. I did tell my step-children about the infection as it impacted upon their own children, but I was terrified to touch and cuddle my grandchildren and tend to their scrapes until after I was treated. The impact on GRO-B has been huge, he has been fantastic but he has had to watch me go through a lot. Our sex life is nil. I am just too frightened I'll infect him. I am not an easy person to live with now and any less of a man would have ditched me a long time ago. It's incredibly upsetting but the grandchildren are now a little more distant with me and they are not as close with me as I wanted. This is because I had to keep them at an arms' length for many years. My step-children, they have tried to understand but I have to understand as well, that their priority was their own children and if they had cut themselves, someone else would have to rush in and sort it out. I was terrified of infecting them. We did have a conservation about this but my step-children don't talk about it now. They knew about the infection and my treatment and were very sympathetic but there was no other discussion. I also have my own daughter GRO-B She was 1 years old when I had the transfusion, it was because of her I signed myself out of hospital in 1985. GRO-B is a very intelligent girl, she has been a rock and I am her mum. I don't think there is anything that would stop her from cuddling me, she wouldn't let that impact her. When I look back over the years, looking back it is horrifying that I could have infected her, I was a proper mum and I was a good mum when she was growing up. I've always been frightened that she was infected, maybe she got tested, I don't know.

She has had the opportunity to be tested but I don't know if she did and I haven't asked.

Section 6. Treatment/Care/Support

24. There has been no offer of support. I should have been given upfront information about what was available, if there had been a counsellor provided, perhaps I may have taken them up on this, but I wasn't told anything about a possibility. Even when I was going through the final treatment I told the clinic nurse, who was called Karen, that I was going to apply to the Skipton fund, she said that I should have told her that I was going to do this earlier and then it was just left to me to do everything. Nobody told me anything otherwise, she was supportive but only to the point that her job required. Now, I don't want psychological support, I wouldn't trust anyone in the medical profession to tell me the truth.

Section 7. Financial Assistance

25. I found out about the Skipton fund through internet searches and in the media.

26. I received £50,000 in an ex gratia payment from Skipton in 2016. The Scottish Infected Blood Support Scheme have also awarded me £1000 a month. I got a further letter from them asking me to detail how severe the impact has been on my life. I told them I have been severely affected and now I am getting £18,900 per annum for 3 years, then after 3 years I have to restate how hepatitis C affects my life.

27. I had to fill in a form, it was quite a lengthy form, quite detailed, this was then sent away to the Skipton Fund and there was a lot of communication back and forward over this period before a decision was made. A hearing was set and then it was rejected, the claim was rejected. That was when I had to find out myself about what had happened to my medical records and find out where the evidence was that I had actually had a blood transfusion. The

policy is that the records are destroyed after a number of years. I went through all my records trying to find something out and I came across a discharge letter which had no details of the treatment I received. In passing it was mentioned by another medical professional in another document which meant that I was successful in my appeal. GRO-B saw me lying in hospital with blood in a bag so he can recall this. On appeal, Skipton said there was evidence and their opinion was that I had been infected through transfusion. There was information in a blood count, 2 days later in 1985 that said that my blood was still very low and this was the reason that they did not want me to leave hospital, the appeal took this as evidence that I had had the transfusion.

28. Your income shouldn't be means tested. The payments I get now are not means tested but what happens if I have to leave my job? There is a possibility I won't be getting better; it will just get worse over time. If I become too ill, this could have a big impact on my work and my financial circumstances. I have passed up on promotions to avoid more stress, I went to university in my 30s before I was diagnosed and I was doing well in my life, I was an office manager and I could have expected to earn more than what I have but I am not ever going to apply for promotion now, it's just not going to happen. I should be earning more than what I am, GRO-B GRO-B GRO-B

29. When I was given the money from the Skipton fund, when it was finally awarded I suppose I should have been grateful, I should have been happy to receive this but I was devastated. I feel like I have been given this money as blood money for the death of my son. I would much rather have had my son alive, this has caused devastation beyond words for my husband and I, we think about GRO-B every day and we feel like the Government have tried to pay us off, we have been given hepatitis C instead of GRO-B

30. Victims like myself should be given information and financially supported in full, these were people that were supposed to look after us and be

sympathetic. They don't treat us as they should. This is a disaster, thousands have been infected and it's just not right to make us suffer more than what we have. My personal opinion is that there has been a massive cover up, there are people in the agencies right up to the top of Government who are involved in this, they would have had to have approved this blood coming in, they just don't care. It's all about money.

Section 8. Other Issues

31. Thompsons Solicitors are recovering my medical records for which I'll be given a copy to review, otherwise I have no documents to provide to the inquiry.

Statement of Truth

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

Signed GRO- B

Dated 27-2-19.