Witness Name: Helen Rice
Statement No.: WITN2251001
Exhibits: None
Dated: 27th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF HELEN RICE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated the 1st October 2018.

I, Helen Rice, will say as follows: -

Section 1. Introduction

1. My name is Helen Rice. My date of birth is the GRO-C 1948. My address is known to the Inquiry. I am retired due to ill health and my husband, John Rice, had to retire earlier in life than he would otherwise have done to look after me due to being infected with hepatitis C. I was infected with hepatitis C when I received a blood transfusion during a gallbladder operation. intend to speak about being infected. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and I and our lives together.

Section 2. How Infected

2. I was admitted to Stobhill Hospital, Glasgow for a gallbladder operation on or around the 7th May 1977. During the operation, the need arose for me to receive a blood transfusion. Four and a half pints of blood were administered to me. There was never any discussion with me afterwards about the risk of being exposed to infection from receiving the transfusion in 1977. I recovered from this procedure and maintained good health until 1999 when all of a sudden I felt incredibly tired and I started to experience an extreme level of pain in my back, which was horrendous. From the point where my back pain developed in 1999, it took a further two and a half years until I received a formal diagnosis of hepatitis C. There were a number of investigations and the doctors finally said to me after a very long investigation, "*It's your liver function, it's not coming back right*". I was then referred on to see a nurse for a liver function test. This was done and I remember the nurse saying to me when the results came back *"No - your liver function test, there's something wrong there"*. At the time I was under six stone, I couldn't move because I was in so much pain with my back and then they sent me for this further test. All this time I had no idea what was wrong with me, but the results came back and the doctor at Stobhill Hospital then told me I had hepatitis C. At the time, I had no idea what this was. He then sent me for a biopsy. The next time I was at the hospital they told me it was in fact chronic hepatitis and now matters had developed to the point I had developed cirrhosis of the liver.

3. As it had been in relation to my liver, it was assumed at the time by the doctors who were involved in my diagnosis, that I was either a heavy drinker, a drug user or that I had been with a lot of men. I have had one partner in my lifetime who I'm still with and I have never been a heavy drinker or taken drugs of any kind. So I didn't fit into any of the categories. When I was diagnosed, I didn't know how I got this disease. I didn't know anything about hepatitis. Most of the doctors I encountered

over the years didn't know anything about hepatitis either so it wasn't established for a long time that I was infected and that the infection was from the transfusion in 1977.

4. I have since discovered through the passage of time that some doctors did know about hepatitis C and that I might have been at risk of contracting it from the transfusion and they chose not to say anything. Although I was registered with a GP Practice, I didn't know who my GP was up until the early 2000's as I was generally a very healthy person. After my diagnosis and from then on, I have had to attend my GP on a regular basis. I am registered with Saracen Medical Centre, 182 Bardowie Street, Glasgow. My GP, Dr Kelly, was lovely, a really nice doctor. At one of my appointments she said, *"When I first saw you, I gave you 3 months to live. There was nothing there, your eyes were dead".* That is how I felt, I felt dead - I was half dead! When I got the results and I had been diagnosed, I went back to her and asked her to explain how on earth did I get this disease? She investigated my records and phoned me 2 days later saying, *"Helen I think it was when you had your operation for your gallbladder."* I am grateful that Dr Kelly had my records and she could find out how I got this illness.

5. No information was provided to me at the point I was infected. No information was given to me about the risk that I would need to be given blood or there was any risk that if I needed to have blood that I might get an infection [redacted] Even at the time when I was diagnosed, I was ignorant to the severity and realities of the condition of hepatitis C. There was no information provided, nobody was able to help me understand; nobody explained what the condition was and nobody seemed to understand how I got it. Every time I went to the hospital they just asked me the same three questions. Was it drink related, related to drugs or related to sexual partners? They never actually explained to me or took account of the possibility I could have got this from a transfusion. As I say, if it hadn't been for my GP and my

friend Margaret talking me through things I don't know when I would have got all the information. The staff at the hospital did not seem to care and assumed that I must have been infected by heavy drinking, drug use or sexual activity. Margaret worked in the medical profession and she typed out a document for me that had a number of things to consider and information about the condition. This is one of the things that I've said previously, I would love for people to be informed about how they can get help, because my husband John and I never got any help whatsoever. It would have been good if a medical professional at the time of my diagnosis had made themselves available to talk through the condition in full. Its better now, you get help now, people understand the problem now. Back then, I used to just lie in bed and say *"I wish I wasn't here"* because I couldn't bear my life. I couldn't be a wife, a mum or a gran. I didn't want to be here anymore.

6. I was not given adequate information to manage the infection, I was given no information, definitely not! As I explain above, the professionals appeared to be ignorant of the condition and what it might mean for me.

7. I should have been told when they found out that I had hepatitis C, I feel as if I should have been told something there and then. When I had the biopsy, a Dr Denesh just told me *"Right you've got chronic Hepatitis C"*, I looked at him, not understanding what this was and he then went onto saying "*...and now because of the virus you've got cirrhosis of the liver. Just see your own doctor"*. That was it, no information, absolutely nothing. We've come a long way since then but it's been very hard. I remember the day I went over to my younger sister's house and my nieces were there and I was telling them. They laughed. They said *"Of all people to have cirrhosis of the liver!"* They couldn't believe it. *"Here we are, drinking lots and you're the one with cirrhosis!"*.

8. Nobody explained what this disease was and how I got the disease, I felt left in the dark and without the support that my family and I needed to understand this illness.

9. Also, information should have been provided to me much earlier about the risk of spreading infection to others. The fact that we all had to be tested in my immediate family was horrible. It was 20 years ago. I gave birth to my daughter after I was infected. It was a natural birth, so if anybody would have caught it, it would have been her. That is the fear, it lay dormant in my system for 20 years and I wondered if it would then just appear for her like it did for me? A few years ago she got unwell and she became tired and I insisted she go to get checked. I insisted that she needed to get her liver checked. She has tested negative, but this is the fear that I have for her.

10. It is said that Scotland is eradicating hepatitis C. They are saying they can cure it. So does that mean you can go give blood? I would suspect that the answer would be no. There is nothing that can confirm that the virus isn't lying dormant.

Section 3. Other Infections

11. I get urine infections all the time, that's murder and that's only part of it. Lots of things happen, your body is not the same, I understand that some of my symptoms are due to age but the majority is down to my condition. The body pain is terrible, the liver pain is horrendous, my bowels don't work right and I feel like I am falling to bits. I've also got an underactive thyroid. I've spoken to a few people in the Scottish Infected Blood Forum, who have confirmed to me that they also developed an underactive thyroid after they underwent treatment for the hepatitis.

Section 4. Consent

12. I was seen by a lot of locums over the years and you get any on duty doctor. I've not looked at my own medical records for further detail on this. When you ask for your medical records you don't get the full records anyway, you just get the condensed version, a synopsis. If you want the

whole thing you have to pay for it now. I am just advised that for providing this statement that this is no longer the case and I could receive my records now and pay no fee. Thompsons Solicitors are recovering records on my behalf and I will then review them. Gartnavel hospital is very good, I get good care, I go there now for my treatments.

13. I don't believe I have been tested without my consent. How would you know if you hadn't given consent? They could be checking for other things. I will need to look at my full medical records when they arrive and check what has been done.

14. Yes, I have been treated without being given full information. I was never told about the possibility that I might blood transfusion at the time that I had my operation or that it may have a risk of infecting me with hepatitis or anything else.

15. I don't know if I have been used for research.

Section 5. Impact

16. The effects are huge. Initially, it was a total shock for me to be told that I was infected with hepatitis C. I am quite a private person. It felt like one day you are fine and then the next, everything has changed. I couldn't go anywhere. John and I had to leave social occasions early. We had no holidays for a long time. We can't arrange anything, as we sometimes would have to cancel at short notice. We don't even say now, we just slip out to avoid putting a dampener on anything. If we are not at an event, friends and family know why. The other impact is just the total exhaustion. My whole life is surrounded by hepatitis C. It has affected every single thing. Like going shopping. John now has to always get the shopping, I can't go. It affects everything. I just have no energy for things now.

17. Mentally it's not nice, I feel like I am a bore. I am clumsy because of my nerves which cause me to drop and break things. I crash into walls and doors and I am also very forgetful now. Then maybe I'll get 2 days and I'm fine and then 4 hours later I am just not well at all. I can't go shopping, I can't do the gardening, even getting my hair cut was a challenge. My hair fell out when I was undergoing the hepatitis treatment (discussed further below) and when it first started to grow back again, it was quite traumatic. At first I had to get my hair more or less shaved before it began to grow back in properly.

18. Cirrhosis of the liver and having an underactive thyroid have been two major medical complications as a result of the hepatitis C. The underactive thyroid has left me with fatigue and the cirrhosis I have already discussed.

19. There was no treatment available at the time I was diagnosed. I was referred to a Professor Mills at Gartnavel Hospital, Glasgow and a month later I got a phone call from him saying that they had this trial treatment with Interferon and Ribavirin available. They asked me if I wanted to take part. I of course said yes. I was advised that the trial would last 6 months. After completing the treatment if there was no change in the virus, there were no further options. At that time, they didn't know the outcome of these trials. It was an investigational drug. It was the only thing they had at that time to give to people. Dr Mills who is probably one of the top liver Professors in Scotland was treating me. If we did have any choice, this was the only treatment that had any chance of working. At this point I was 6 stone and dying, I was clutching at straws. It was, however, a horrendous treatment. I got past the 6 months' mark and carried on to the full year. There were many side effects. After the initial 6 months I was told that if there was no improvement following the treatment, I would just be sent home to die, it really was a horrendous time. I remember the day we found out if I was to die or continue on with the

treatment. To know you are waiting on someone to confirm if you will live or die; this was a very dark day for my family and me.

20. The medical profession has still never confirmed that I contracted hepatitis, because of the blood transfusion that I received in 1977. For other people, there have been medical records that have gone missing and also medical records have been doctored, it's ridiculous. People are really ill so it's hard for them to fight. It's really hard for the infected but also really hard for the affected. When you are watching your partner die, it's heart-breaking.

21. I've never had obstacles to treatment.

22. There wouldn't have been any treatment at the time other than what I was offered. Even a lot of the consultants didn't know about Interferon and Ribavirin. It's the same pharmaceutical company that supplied this. It was a trial. I don't think there was anything else at the time. There was a time when my whole body "broke out" in a rash, and Professor Mills took me off the Ribavirin tablets. I had been on the treatment for 3 months and I thought "oh no, this is not working". I was terrified I was going to die, but when the 6 months came, it had made it that far. That is one of the big impacts of the period, the realisation that I was getting this treatment, and if it did not work, I would be sent home to die. I still live with the possibility I might die now. I get the scans twice a year now because I have cirrhosis. Deterioration in my liver could happen very quickly, it could turn very quickly to cancer of the liver which is why they check me twice a year, which is good.

23. Everything was painful, I was clumsy, walking into walls, only able to walk at a certain pace. It was a crazy time. I used to walk everywhere, to my mum's, work, everywhere. I really enjoyed walking. I have no concentration now as well. I used to do 'Take a break' crosswords all the

time, but when I tried later on, I was not able to. It's now been about 15 years since I've been able to read a book and I loved to read previously. I dearly miss this.

24. One of the most horrendous times for me was when I was going through the treatment and my hair fell out. I had not a single hair on my body at one point. It was a side effect of the treatment. I was covered in rashes and itching, all over. It's like a catch 22, if I hadn't got this treatment at the time I would have died, but the Interferon and Ribavirin is slowly killing people now. This is the worst disaster in the NHS and the least publicised. We have had a terrible time in Scotland and the Scottish Government has helped us a bit but more needs to happen. Thompsons have been great too. The Government should be helping people, instead of helping to raise the barriers.

25. During the treatment, I describe myself as being like a drug user going through withdrawals. I was itchy all over, I couldn't stop moving. I couldn't sit comfortably as I was constantly twitching and John felt awful as he could see how uncomfortable I was, and there was nothing he could do to help. From there I had to go to the Western Infirmary, Glasgow where I received a number of potions and treatments. They gave me I think, 5 or 6 prescriptions. I couldn't even go to the chemist and get the prescriptions filled out because I didn't have any money to do so. That was in the1980s. I just took one prescription out of the 6. That's how bad it was, that you couldn't even afford to go and get a prescription. We had always worked, so it was very hard.

26. The treatment caused my teeth to deteriorate; they were falling out so I went to see a dentist. At the dentist I experienced one of the most embarrassing moments of my whole life. I reported to the receptionist in the waiting area and explained quietly my situation only to be told, in a very loud manner that "*We don't deal with hep Cs in here*". I went to another dentist, and the same thing happened. Everybody was ignorant at the time; it was like the AIDS epidemic. People are ok now. It's not a

disease you can catch off anybody easily. It does happen, but not easily. It does make you feel dirty though. Eventually I sat in the house and I phoned around dentists and asked them if they would treat me. Eventually I got one, and I spoke to the receptionist and I asked her if the dentist would see me and then the next thing the dentist came on the phone and said *"I don't understand why other dentists don't treat you. All dentists have gloves and masks now. There's no way we could get infected from you".* He said you have been treated appallingly and that I should have taken it to the ombudsman. I didn't take it further. That dentist was very nice; I have not experienced further incidents like this at the dentist since then.

27. I don't really have a social life now. It's a very limited. If we do go out, John is limited as he can't have a drink as he has to take the car everywhere, so I can go. I have missed out on many social events, many big landmark parties like my granddaughter's 18th and 21st birthday.

28. I was so embarrassed originally; the stigma was terrible. My friend knew and my family knew but that was it. My friend, who was a nurse, explained the illness a wee bit but I still didn't fully understand the whole thing when I was first diagnosed. The guiding light was actually, watching the news where I saw our friend GRO-A . GRO-A was infected as well. After the story aired, I phoned him and I explained. That's basically how we got onto Thompsons Solicitors.

29. When the Penrose Inquiry was coming out I was asked to do an interview. I felt that I couldn't because nobody really knew that I was infected. I was embarrassed but then I made the decision to tell my family members who didn't know, so I told my sister and my nieces and they were all very understanding and concerned. They said *"Why didn't you tell us? We knew you were really ill but we didn't know what was wrong with you".* One thing my sister said was *"I don't understand why you didn't tell us?"* I explained that I was embarrassed. Her response was, *"Did you not think that people wouldn't know you"?* I obviously know that now, but not at the time. That is the reason I agreed to be a core participant for the Inquiry. I started to get

involved with the groups and now I hear some of the stories and they are really tragic. Some people are no longer here. Within the group we have great campaigners and managers, GRO-A, GRO-A, GRO-A GRO-A are really great. We meet people all the time and we see a variety of problems and a number of problems that keep appearing for everyone.

30. There were no educational effects due to infection and the point in my life when I became aware of the hepatitis C diagnosis.

31. I had to give up work, I signed off sick and my boss told me "*Don't you dare come back until you're better*", in a kind way. Every day they saw that I was getting thinner and thinner. I did go back to work eventually and they spoke with me. They said that because it was taking so long between each hospital appointment, around 3 months at the time and I was waiting for the tests on my liver they offered private insurance. They offered that to me and said *"Maybe you'll get treated quicker".* They were so nice. I worked for the company for maybe about 6 months. After that point, I had to reduce my hours to part time. I've always worked, for different employers obviously, I can't recall specific details for dates now. My role was a sales assistant; I have always worked in ladies' fashion. In the end I literally couldn't work. I couldn't even climb the stairs and go to the stock room. I couldn't even boil a kettle, but my colleagues would help with a lot of the heavy work but this was the point I realised I had to give up work completely.

32. Neither John or I were able to work because of this. We had no money as well as dealing with the illness. With no work and no money coming in, John went to the Department of Work and Pensions for support. He was a self-employed joiner and they said to him *"If you are self-employed, you must have tools*". He said yes, and they said that we should sell them. We had two children then, this was simply beyond inadequate. What would have helped at the time, would have been if the DWP had been able to support our family and not leave us on our own. If it hadn't been for my mum, we wouldn't have been able to pay the bills because we had no money. It then became a continual matter of trying to agree things with different companies. So we were on the phone to the gas

board or to the phone company to say, I'll be late with this and late with that. When we were both working, we used to have 3 or 4 holidays a year, but that all stopped and it stopped for many years. At that time, it added to the overall problem. All because of a really serious illness that nobody had explained what it even was.

33. It affected John a long time. We have known each other for 52 years and we have been married for 47 years. I have always been a healthy person. Now, he has to do all the housework and chores. He is always very worried about me. My kids are grown up now, and we have grandchildren who are all off and doing their own thing, so they are ok. I used to see my children and grandchildren every day, but when I was ill there were days/weeks where I couldn't see them at all. My immune system was completely wiped out, so any coughs, colds or any normal childhood illnesses would have been very harmful to me. This worried the children as this confirmed to them that their gran was ill and they were always understanding about this.

Section 6. Treatment/Care/Support

34. John has done, and continues to do, most of the day to day care for us. He takes care of the shopping, housework, gardening and getting me to and from medical appointments. The only support I received for the mental side of things was a psychiatrist that I saw twice after I started treatment. I didn't get any help or counselling. With hindsight this is something I think I would have benefited from. There are a lot of things that I couldn't talk about with my family and it would have helped to have had that option. It was never offered. I know I went through a time when I was very down and I was sent to a psychiatrist who gave me a tape with nice music to try and relax me. It was during the first 6 months I was on treatment, I went to this psychiatrist because of all the side effects. I just had to lie in my bed and just try and calm down, that was it, that was all the help I got. The information was communicated very badly, and the support was not there. You would have to ask the questions to get the

answers and they were a wee bit lax, (the hospital), there wasn't much information. We had to get our children tested as well. The help was very slim. We get help now through Haemophilia Scotland and SIBF.

Section 7. Financial Assistance

35. Originally we saw an item on the news and an interview with GRO-A about the financial help. I cannot recall when this was.

36. The first payment I received was when Malcolm Chisholm was the Health Minister. He gave us an ex gratia payment. He told us it was not compensation. It was from the Skipton Fund, through Thompsons, that we got that payment. We got £20,000 in 2003/2004. As I had hepatitis C and then cirrhosis, I received a further £25,000. It was such a boost. We tried to get benefits but being self-employed it was quite difficult. We kept being knocked back. The payment didn't affect our benefits, which helped and took a big weight off our shoulders. Burdens like not being able to pay the mortgage and the bills. A lot of infected people will tell you that they are always cold. The heating has to be on all the time and the heating bills are extortionate as a result of the illness. Patrick McGuire has guided us through this which has helped a lot. The financial help has helped but still, more needs to be done. What is scary as well is that there will be more and more people with the disease. The fight had started with GRO-A It helps people pay bills but you don't get pleasure out of it though because everybody is ill. Once the bills are paid there are more important things than money but this is a big part of it.

37. There was no problem about applying for financial help. We didn't even need to apply the second time. SIBSS contacted us later and we just had to give our bank details. So for us, it has been very smooth. It was just a case that you filled in an application form and that was it the first time.

38. John and I have had no problems applying for financial aid. We struggled for many years but now we are fine financially thanks to the campaigning through the years.

39. No preconditions were applied to our application. It was just this ex gratia payment. When we had to apply for benefits that was horrific. We had to go to the panel 3 times to apply. There was a doctor that asked me what medication I was on and when I told him, he had never heard of it. I was then called to go back again and at the 3rd meeting they asked me if a doctor had been to our home. I said no and they said well a doctor will have to come to your home before a decision is made. Anyway this doctor came and she asked me a lot of questions and it turned out she was known to be strict with the rules. She would find any reason to knock an application back. My husband and I were talking to this doctor and the first thing she commented on was my ankles being swollen. Then she felt my back and she said she could actually feel my liver it was so swollen. She was in for about an hour and then she went away and sat outside our house writing a report. We were then called back again and the person at the panel said to us that, my form had been all over the building. The doctor had handwritten it which is unknown for this doctor to do. We were the first family that she said were absolutely to get benefits as soon as possible.

40. I am happy with the financial assistance that we get but there are a lot of other people who are still not getting the financial help they need and deserve. The stage 1 widows have had a terrible time and there shouldn't be 2 stages. People who have contracted this illness through no fault of their own should automatically be entitled to financial help. It is known that some stage 1 people who contracted the infection are worse than some stage 2 people. If you think about your working life, if you had to stop work because of this, how much financial help would you need for the rest of your life? It could be up to a couple of million over a course of a lifetime and they have just given out a few thousand. There

are people who are really ill but are being forced to work, sometimes at a lower level and lower pay grade, through pain and extreme exhaustion as they do not have the financial support they are entitled to. It shouldn't matter if you're a window cleaner or a QC. If you can't pay a mortgage or buy food due to ill health, help should be available.

41. Now we want the truth! Why did this happen? Why are they hiding the truth? Why when they found out how bad this was affecting people, did they continue on with this treatment? People in government should stand accountable. It's not to do with the NHS. In my view, it's to do with the government and the pharmaceutical companies. For me, that is where the deals were done.

Section 8. Other Issues

42. Haemophilia Scotland and SIBF work together, you will probably get a further statement from them at some point.

43. I wish for Thompsons Solicitors to recover my medical records on my behalf and that Thompsons Solicitors and I be given the opportunity to review these in full.

Statement of Truth

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

Signed GRO-C

Dated 27/2/2019