Witness Name: Dorothy Anderson
Statement No.: WITN2074001
Exhibits: NONE
Dated: 5 November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DOROTHY ANDERSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 November 2018.

I, Dorothy Anderson, will say as follows: -

Section 1. Introduction

1. My name is name is Dorothy Anderson. My date of birth is GRO-C 1945 and my address is known to the Inquiry. I am James Anderson's wife. I intend to speak about my experience of becoming infected with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

Section 2. How Infected

2. In June 1979, I attended Stirling Royal Infirmary for an operation to remove a kidney stone. It was not an emergency. It was a standard operation and I had been waiting for a bed to become available. I went in the day before the operation. This was at the end of June. I had blood samples taken, my heart was checked and all preparations were made for my operation the next day. The next morning I was told where I was on the waiting list and preparations were again made for the operation. Around half an hour later, a nurse came to speak to me. The nurse said she was very sorry but the operation was not going ahead on that day due to my haemoglobin level being too low. For this reason, the anaesthetist would not anesthetise me. I was given a drip for blood and plasma. This drip was set up and I definitely remember that I had at least two bags of blood. I am not sure if there was a third bag. I had the operation the following day. I did not think about this anymore after the operation. I had absolutely no reason to think that there should be any problem. I did not think about it for years. I believe that infected blood was given to me at that time. No information about the risk of becoming infected with hepatitis C was provided to me at the time of the transfusion. Nothing was said. I was just told that I would require blood. It never entered my head that there could actually be any risk linked to the transfusion.

3. Fourteen or 15 years ago, I made a visit to my doctor because I was constantly tired and I thought that something had to be wrong to cause me to feel such extreme tiredness. I wondered if it could be my thyroid or if something else was causing me to be so tired all the time. On that occasion, the doctor took a blood test and sent it off for analysis. Afterwards, I received a letter with just one line saying that I had hepatitis C. I was really taken aback. I made an appointment to go and see the doctor. He was not particularly helpful. He said that he would write to the specialist at the Victoria Hospital in Kirkcaldy and ask him to make an appointment for me to go and see him. At that appointment I was seen by a specialist in Infectious Diseases called Dr. Bhattacharya who examined

me a very brief explanation of Hepatitis C. I gave blood samples and had routine checks such as weight and height taken. I continued to attend this clinic for annual check-ups until I read out about the Inquiry into Infected Blood and decided to contact Thompsons Solicitors. At that time, I was told by Thompsons that nothing could be done about my case because it was time-limited and I was too late to apply. I later received a letter last year to say that the inquiry was being opened again and I attended an open meeting in Dundee.

4. I attended my appointment with the specialist at Kirkcaldy hospital. The specialist was Dr Bhattacharya. I am sure he was a very good doctor in his field but I did not find him a good communicator. I was not getting any real information from him. He gave very brief answers to any questions asked by me. I do not know where he was from originally, but his English was limited and it was difficult carry out a detailed conversation with him. He was based at the Infectious Diseases Department. The nurse, Karen Thompson, who worked at that same department was actually a lot more helpful than Dr Bhattacharya. I found attending the clinic very upsetting as it was only when I attended the hospital that I fully addressed the fact that I had Hepatitis C. I refused to think about it at other times and did not even tell my family that I was infected with the disease. When I asked Dr Bhattacharya what my options were, he offered a nine-month course of injections with interferon and informed me that because of the strain of Hepatitis that I contracted, which was the worst one, the outcome was no higher than 50/50 or perhaps even less. I cannot exactly remember what kind of hepatitis C I had, but I had the worst possible strain.

5. My immediate reaction to being told that I had Hepatitis C was to ask if I could, in any way, infect anyone else with this disease. I knew nothing about hepatitis C at all. Dr Bhattacharya informed me that the only way in which I could infect another person was through my blood being mixed or contaminated with someone else's blood such as by a cut. He said there was no other way that I could infect anyone else. At that time, I had a

young grandson and I didn't want to put him, or any other member of my family at risk if I, for example, gave them a kiss. The doctor told me I could not pass it on through saliva. It really affected me badly and I relied on nurse Karen Thomson and another nurse whose name I cannot remember. They offered me counselling when they realised that I was upset. The doctor did not give me much information at all. The doctor did mention not drinking alcohol to excess. I had read up a little on the internet and knew that it affected the liver. I drink very little alcohol so this did not really affect me. However, alcohol was the only thing that was mentioned at all about hepatitis C and lifestyle. I found it difficult when I asked if anything had changed. This is because I only ever had yearly appointments and I was not advised of anything from one year to the next such as results of blood test etc. in between appointments. The doctor always said there had been no changes. When Dr Bhattacharya retired another specialist took over, but the same nursed remained. At that time I read about a new treatment that had come out and contacted the nurse to ask if I would qualify for this treatment and she subsequently asked the specialist. I then received an appointment to see the specialist. The new specialist asked a few questions and said that she would get me on the new programme. This entailed injecting myself once a week and I also went to the clinic once a week and later on just once a month. I cannot remember how long the treatment lasted. At the end of it, tests were done and it was found that the treatment had been successful. No one asked me if I wanted that treatment and if I had not taken the initiative, I would not have received this treatment. I cannot remember the specialist's name. However, I can remember that she was a female doctor and that I did not see her during my treatment or at the end of the treatment. It was left to the nurse, Karen Thompson, to oversee my treatment right through to the end.

6. The doctor at my local health centre said that they had only just started testing for hepatitis C when I went to see him about feeling very tired at all times. I could not, therefore, have been told earlier about the hepatitis as it was not normal practice to test patients for it before this time. My initial

information was given to me on that day. I was simply told that I had hepatitis C and that it affected my liver. I tried to speak to Dr Bhattacharya about my life expectancy and was told that everyone is different. I found it really difficult to gain any real information at these clinic visits and found that talking with the nurses gave me more of an insight in the illness. I also found information on the internet but I would rather have heard most of this information from an actual doctor.

7. With regard to the way in which the results of tests and information about the infection was communicated to me, the first thing that really surprised me was the way in which my doctor told me. He simply sent out a letter with just one line saying that I had hepatitis C. I found this to be very bad practice and feel that he should have asked me to make an appointment to see him at the surgery. I felt, and still feel, that this was a terrible way in which to communicate news of this kind to a patient. My first thought was that only drug addicts contracted Hepatitis C and as I had never had any connection with drugs nor knew anyone who took drugs, that this letter must be a mistake and had been sent to me in error. I thought that it simply could not be me. Even when I did go to see the doctor, he was still not particularly helpful. When I asked him why this had never been picked up on other occasions when I had blood samples taken, he simply replied that they had only just started testing for hepatitis C. I was extremely upset at this consultation but did not feel that my doctor realised how shocked I was by this development. My health in any other respect was never discussed other than the fact that I should abstain from drinking alcohol and to this day not one of my doctors at the GRO-C has even mentioned or spoken to me about the fact that I had Hepatitis C. My local surgery is called GRO-C and it is located in GRO-C GRO-C The only occasion in which Hepatitis C was ever discussed with me at my local health centre was when the nurse, Karen Thompson, suggested to me that I should apply to the Skipton Fund, so I went to the health centre to see my doctor as I needed to fill in forms with my medical background. On that occasion, I spoke to Dr Burnett, who gave me

photocopies of my medical records. However, when the form was sent to the Skipton Fund I was told that there was absolutely no proof that I ever had a blood transfusion at the time of my kidney stone removal operation as it was not noted on my medical records. The medical records only reflected me having an operation but not a blood transfusion having been received.

8. No real information was provided about the risks to others becoming infected as a result of my Hepatitis C. As I previously mentioned, I was only told that if I had a cut and someone else had a cut, then cross-contamination could occur. I knew I had a blood transfusion and in between receiving the letter informing me that I had hepatitis C and attending the appointment, I thought about the ways in which I could have been infected and I concluded that the blood transfusion was the only way in which I could have been infected. The doctor said that was possible, but it was not discussed further. The doctors have never admitted that this was the case and an explanation has never been offered to me.

Section 3. Other Infections

9. To the best of my knowledge, I do not believe that I have received any infection or infections other than Hepatitis C as a result of being given infected blood.

Section 4. Consent

10. Over the years, I have had many blood tests for other things since the blood transfusion at the time of my kidney stone removal operation. Dr GRO-C, who is no longer at the practice, was the doctor who sent me the letter. He was the one who said that they had only just started testing patients for hepatitis C. I do not know if Dr GRO-C meant the practice had just started testing patients for hepatitis C or the country had just started testing patients for hepatitis C. I do not know whether I have ever

been treated or attested without my knowledge. I don't feel that I was treated for Hepatitis C before I knew I had it. I do not know if I have ever been tested for Hepatitis C before the time when I was informed that I had the disease.

11. I do not believe that I have ever been treated or tested without my consent.

12. I do not think that I have been treated or tested without being given adequate or full information. The only thing is that Dr Bhattacharya provided very little information. If they knew at the time of the transfusion that the blood was infected, then they should have warned patients of the risks but I don't know whether or not they knew.

13. I do not know whether or not I have ever been treated or tested for the purposes of research. I suppose in some ways, once your blood is taken, you have no way of knowing what is then done with this sample. I did not agree for any of my blood to be used for research, but then again I was never asked.

Section 5. Impact

14. The mental effects of the illness were worse than the physical effects to begin with, as I was upset for a long time and in a lot of ways I still am upset. From the outset, when I was told that I had Hepatitis C, I felt violated by the fact that I had someone else's blood inside me, which had given me Hepatitis C and I did wonder what other things I might have contracted. I was fine when I did not have to think about it, but hospital visits were hard for me because they made it all come out again. It was hard not being able to understand the situation and not getting any help in order to understand it. You actually feel like a leper, despite the doctor saying that the infection is not easily passed on. I continued to keep it to myself because I found that when I did talk about it I became very upset

again and therefore it was easier to just not talk about it at all. It was very hard to be affectionate with my grandchildren and with my husband. Even after the treatment, there are still days when I wonder if I have really got rid of the infection because I still feel extremely tired sometimes. At these times, I wonder if the infection is back. I thought about phoning the nurse again for a check-up, but I do not have the courage to go through it all again. I was never told that I was clear of the infection only that I was in remission. Basically, the illness gave me extreme tiredness. It was a real effort to be able to do normal things. These day-to day things became difficult due to my lack of energy.

15. I do not think that any further medical complications or conditions have resulted from the hepatitis C itself, other than my liver being affected.

16. No treatment was offered after Dr Bhattacharya left. I was simply just being monitored and my blood, weight, and other details were checked. My consultations were really very brief. When Dr Bhattacharya left, I had an appointment with the new specialist and shortly after I read about the new treatment. Otherwise, I would have carried on as usual. When I read about the new treatment, that is when I contacted the nurse about the treatment. The treatment was not pleasant. I was quite sick after each injection. I was warned however, that this would happen. I had to administer injections weekly. I was physically sick, that is, vomiting and I felt really cold and shaky. I had to wear layers of clothing in order to try and mitigate the cold that I was feeling. Then I would vomit. My hair got thinner and thinner and has never recovered. My nails were affected and they split from the base of the nail up to the top and to this day I cannot grow them as the vertical split is painful. My memory loss could be due to age or it could be related to the treatment. The hair loss was really bad and so was the sickness. The memory loss could well have been due to the treatment as that was when I really started to notice it. The treatment was successful. I was told that the Hepatitis C was in remission. They did not say that I was a hundred percent clear. They cannot say that due to

not really knowing if it is or not. I have never been asked to go back to hospital to be tested again and I don't know why.

17. I do not think that I faced any difficulties or obstacles in accessing the treatment, other than the fact that if I had never read about it, then I would never have received any treatment. Access to treatment itself was not unnecessarily difficult, but I was not offered the treatment, I had to ask for it. Again the nurse involved was my contact and helped greatly.

18. I do not know whether or not there are treatments that were not offered and should have been made available to me.

19. I would not say that being infected with Hepatitis C has greatly impacted upon other medical treatments that I have received. However, I had an operation in Ninewells Hospital in Dundee when I was rushed in by ambulance. This was after I already knew that I had Hepatitis C. On that occasion, I brought to the attention of a nurse that I had Hepatitis C and was quite upset by the way in which I was treated. Her reaction was to say "Oh no!" and draw back. Intensifying my own feeling of being like a leper. I can't remember who it was because I had been given morphine. I have had no other such experiences, but it was shocking that someone in the medical profession would react that way.

20. I did not tell my daughters at all that I had Hepatitis C. I did not want them to worry and I didn't want to have to talk about it. I just wanted to deal with it myself and to keep it locked away. This was how I coped in between appointments. Consequently at my clinic appointments when I had to discuss it I became extremely upset. I felt that I was not being honest with my daughters but felt that if I did tell them then I was only going to cause them worry and there was nothing they could do to help me. For many years, there was no cure for my Hepatitis C and the only treatment that was offered to me by Dr Bhattacharya had very limited chances of success. This also influenced my not telling my daughters about the

illness. Also, I would not have been able to look after my grandchildren and I did not want to stop doing this and cause more trouble for my daughters. I had my treatment about five years ago, maybe four. I did not tell any friends, just my husband. I did not want to talk or even think about the Hepatitis C because that is how I coped.

21. I also feel that there is a stigma linked to having hepatitis C. This has affected me. It stopped me from talking to people about it. Even though you know how you contracted Hepatitis C and that it was from a blood transfusion, it is still a horrible thing to have and to be associated with.

22. By the time that I started treatment, I had already stopped work. When I stopped work, I did so in order to look after my mother, who was ill. She didn't know that I was infected with Hepatitis C either. My mother died in 2001 and I did not find out that I had with Hepatitis C until 2002 or 2003. I did not go back to work after my mother died as shortly afterwards I started looking after my grandchildren. If I hadn't had any grandchildren to look after, I would perhaps have gone back to studies, but that was not the case.

23. Contracting Hepatitis C did not really affect my finances. It affected our lifestyle because I did not have the energy to go and do things such as going out, or walking which I used to like. It also seriously affected my relationship with my husband as I was always conscious of having this illness and no amount of reassurance stopped me from worrying that I might infect him. I am really disappointed in my own doctors because they have taken no interest at all in my Hepatitis C and they have not even enquired as to whether the treatment was successful.

Section 6. Treatment/Care/Support

24. Shortly after a meeting with Dr Bhattacharya counselling was offered but I never attended. The reason why I chose not to attend counselling was a combination of things. I didn't see that speaking to a counsellor would make the situation any better as they could not cure me. If it had not been for nurse Karen Thompson I do not know if I would have got through it. My husband said I should maybe go to counselling. However, when you are in the middle of something like that, it is difficult to see your way out. Karen provided me with her personal telephone number to call her at any time if I needed to talk. This was her mobile telephone number. No other care or support was provided. If I had not had Karen's telephone number, I would not have been able to ask about the new treatment when I read about it.

Section 7. Financial Assistance

25. When I applied for financial assistance from the Skipton Fund, I was told that there was nothing in my medical records to say that I had received any blood transfusion whatsoever.

26. I only found out about the Skipton Fund through the nurse informing me. Then I had to look online and apply myself. The first time that I came to Thompsons, I was told that it was time-limited.

27. I have not received any payments whatsoever from any trust or fund.

28. When I sent copies of my medical records to the Skipton Fund relating to my kidney stone removal operation I don't think that these records go back far enough. I am not sure what happened to the records. I think that my medical records or at least part of them are missing. That is why the transfusion is not in the records. That was, therefore, an obstacle that prevented me from receiving any payment from the fund.

29. I do not think that there were any other pre-conditions imposed on the making of an application for financial assistance.

30. I was never made aware that there was financial assistance and did not know that there was any. If Karen had not told me about it, I would never have known. When I contacted Thompsons the first time, I still did not know what the situation was regarding financial assistance and still don't know. I was too late to be included in the Penrose Inquiry.

Section 8. Other Issues

31. At the beginning, I was not aware that there was any financial side to the whole business of being infected with Hepatitis C. I never even thought about it. When I came to Thompsons first, it was because I read about the Penrose Inquiry in the paper. If I hadn't read the paper, then I wouldn't have known. I think the GPs should be telling their patients that they can apply for compensation. Otherwise, people like myself will be left in the dark.

32. Regarding anonymity, my family now know that I was infected with Hepatitis C, except for my grandchildren. I am aware that my statement will not be made anonymous unless I contact Thompsons again regarding this matter and specifically request that my statement be made anonymous. However, I still require some more time to consider the matter and will contact you in due course.

Statement of Truth

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

Signed GRO-C

Dated 4.3.19