Witness Name: LOIS WILKINSON
Statement No: WITN0746001
Exhibits: 0.
Dated: May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LOIS WILKINSON

I, Lois Wilkinson will say as follows:-

Section 1. Introduction

1. My name is Lois Wilkinson. I was born on GRO-C 1961. I live at GRO-C GRO-C Manchester, GRO-C. I was infected with Hepatitis C (HCV) when I was received a blood transfusion after giving birth in 1989.

2. I am married and I live with my husband. We have 4 children and 5 grandchildren. My husband continues to work and I was made redundant about 5 years ago. I worked as a substances misuse practitioner. I am now retired on the grounds of ill health.

3. This witness statement has been prepared without the benefit of access to my medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. I received a blood transfusion during the birth of my son GRO-C on GRO-C 1989 at Tameside Hospital in Ashton-under-Lyne. The donor unit reference numbers are 220952 and 198270. I had a difficult labour with GRO-C as he was a very large baby which resulted in an emergency caesarean section under general anesthetic. I went into shock and I have no recollection of receiving a blood transfusion. I understand that I was given the blood on the ward and not in the theatre. I received two separate transfusions the same evening after the caesarean.

5. After the transfusions nobody spoke with me about any potential risks of receiving contaminated blood. I was not even asked whether or not I wanted a blood transfusion and I do not recall being asked if I consented based on religious grounds. I do not recall the specific names of any of my treating doctors as it was all so frantic and quite frankly it was all a bit of a blur.

6. My son GRO-C was very poorly when he was born. At the birth I was told that his head was down, however in reality he was actually sideways in the womb. As a consequence during my contractions his airways were trapped and it was imperative that he was delivered as soon as possible. That was the reason for the emergency caesarean.

7. I have experienced so many health issues for years and I have seen so many doctors but it wasn't until 2016 that I was diagnosed with Hepatitis C. I was under the care of Dr Patel who is a Gastroenterology & Hepatology Consultant at Tameside Hospital. I had been seeing him for about two years because I felt so terribly unwell. However he kept telling me that I looked healthy but I told him I felt terribly unwell. I remember going to see him with a list of things that I thought should be checked and that included Hepatitis C.

8. I went for an appointment in December 2017 and on that occasion I saw a different Consultant. I told him about my pains and out of the blue he said, 'that will be down to your Hepatitis C'. I replied saying 'what do you mean my

Hepatitis C?' He told me that the test results for the Hepatitis C were confirmed in December 2016. I had actually seen Dr Patel in March 2017 and August 2017 and he never mentioned anything to me about having Hepatitis C. I can only assume that this new Consultant had actually read my file.

9. I was so shocked and he was so abrupt in the way that he told me and I asked him where it came from. He was so matter of fact in the possible ways I could have been infected. He stated through the misuse of drugs, sexual intercourse and/or alcohol abuse. I didn't know what to think as none of those applied to me and I felt he was out of order in being so cold and he didn't say anything about how to keep safe or what to do.

10. I asked him what the next steps would be and he told me to get in touch with Dr Patel's secretary and that it was not really his problem. I was given no information about how to manage my infection and to protect my family. I was not even given a leaflet. He brushed me off because I was not his regular patient.

11. I called Dr Patel's secretary and I was told that he would not be able to see me until February 2018. However I did get to see him in January 2018 but when I did it wasn't helpful as he didn't give me any information.

12. I think I should have been provided with a leaflet at the very minimum. To let me walk out of there without any information from a nurse or discuss possible treatments was an absolute disgrace. I felt so strongly about it that I actually made an official complaint.

13. Initially I was so numb when I found out, I felt so alone and I felt that I couldn't share it with anyone. There is such a stigma that comes with it and I was still trying to work out in my head how I could have possibly been infected.

14. I could not have contracted the infection through my line of work because of my training. I never had any injuries at work that could have possibly related to me actually getting infected.

15. I was referred to Dr Bonnington at North Manchester Hospital in the Infectious Diseases Department and I had an appointment in March 2018. At that appointment Dr Bonnington explained everything to me.

Section 3. Other Infections

16. I was not infected with anything other then Hepatitis C.

Section 4. Consent

17. I would not have known whether or not I gave consent to being tested. I was not aware I had ben tested for Hepatitis C. I was unaware of any of the potential problems I may have had until being diagnosed in 2016.

Section 5. Impact of the Infection

18. I had been poorly for so many years but I was given so many other reasons why I felt so ill. I currently suffer from cirrhosis; type two diabetes, gallstones, fibromyalgia, arthritis, bowel and gastro problems, fatigue, low moods and compressed discs in my back. I lost my job due to sickness as I felt so ill all the time and I could not concentrate.

19. It was not until I went to the infectious blood clinic in March 2018 that I actually discovered where I had contracted Hepatitis C. I also had many tests done and to also determine what strain of the infection I had contracted. Treatment options were discussed with me and I was told that we had to apply for funding for the treatment. I was told that it could take up to 12 months.

20. I had a follow up appointment with Dr Bonnington in April 2018 where all my test results were discussed with me and I was given a treatment plan. I felt so much better speaking with him as he gave me so much information and addressed my concerns. Dr Bonnington explained that there was a new treatment which was

a 12 week course and consisted of taking three tablets, three times a day. The medication was called Marvelon. During the treatment I was tested every 2 weeks, then every 4 weeks to check my Hepatitis viral load. GRO-C were also tested which was very traumatic because I had not told GRO-C anything about the infection and that GRO-C. Fortunately GRO-C GRO-C but it was such a difficult time having to explain everything to them.

21. Dr Bonnington told me that I had significant scaring on my liver and that the damage was not recent and he thought that it was probably at least 20 to 30 years old. He also said that he could get rid of the virus but not the amount of damage that the virus had caused.

22. I started my treatment for Hepatitis C at the end of May 2018. I could have started it in early May but my son Michael was getting married in France. I did not want to start the treatment before his wedding because I did not know how it was going to make me feel. I was also concerned that purchasing travel insurance would be much more expensive.

23. I didn't find the treatment easy and I suffered with extreme fatigue. I felt sick and my skin was itchy. I did not want to do anything or book anything because I did not know how I would feel.

24. Some way into the treatment, I don't recall at exactly what point, I was told that the virus had halved. By the fourth week it was 90% gone. My last test was in March 2019 and there was no sign of the infection. I have been told that I need to be checked once a year and this can take place at my GP. I have since been immunised against Hepatitis A and Hepatitis B as I was told that I am more susceptible to getting them.

25. In terms of the psychological impact I became really quite low and I think that it is fair to say that I actually suffered from depression. I became really introverted and I felt that people were saying that all my pain and suffering was in my head. I used to say to my husband that I didn't think anyone believed me when I would tell them how ill I felt all the time.

26. I had been suffering with pain in my joints and the joint specialist told me that the pain I was experiencing in 2016 wasn't normal. This was before my Hepatitis C diagnosis and the specialist made contact with my gastrologist who told him that the pain was normal for me because I had been having the pain for 20 – 30 years.

27. It really does not make sense that I was not diagnosed years ago. I feel that I have had so much treatment for other things that would not have been necessary if I had been diagnosed correctly with Hepatitis C. I was diagnosed with type 2 diabetes, 19 years ago and suffered to control my blood sugar levels and I had to inject myself with insulin. Since my treatment I have not been using insulin and now I only take tablets. I am pleased to say that I now have it under control.

28. I have had a lot of abscesses and I am sure it is a result of the Hepatitis C. 15 years ago I had to have 12 teeth removed all because of the abscesses. I have also had abscesses on my leg and my back and these had to be removed.

29. I have also suffered with joint problems and I have been diagnosed with Fibromyalgia. I used to have a constant brain fog whilst at work. I used to really notice it when I had to give a presentation as my mind would go blank. My computer skills were also really slow.

30. I have been seeing Mr Curren who is a Consultant Colorectal Surgeon for 12 years as I have had so many issues with my bowels. He had originally thought my bowel problems were due to nerve damage but since the diagnosis he has said that it is due to the HCV. I have had a tube in my bowel for the last two years that I have to flush every day. Mr Curren is the only Consultant in the country that does this type procedure. It will stay in for four years and has to be changed every 6 months.

31. After I had my daughter Abbie I had to have a hysterectomy because I had so many problems with my periods.

32. I am still on medication for the HCV and I take a variety of medications. For my back pain I take pregabalin and I am on numerous pain killers including paracetamol and codeine. I am also prescribed tramadol for the pain in my joints and my abdomen. I suffer with sickness and when I need it I take cyelizine. I do not want to become dependant on this drug and I feel that I can control it better if I take it sporadically.

33. Since I have had the diagnosis I feel like I finally know what has caused all my health problems. However I am of course angry and worried because my specialist has informed me that I have cirrhosis of the liver. I am unsure what grade it is as no one really knows and I seem to just be told different things.

34. Now I feel physically tired all the time and sometimes I feel like a waste of space. Both my husband and I find it really quite upsetting. We should be enjoying our kids growing up but I feel sick most days and eating food is hard, especially eating out.

35. We also want to spend our time travelling but travel insurance is so difficult to get and so expensive. It probably costs more for the travel insurance then the hotel and the number of questions that I am asked is ridiculous. I think that a lot of people think I am or I was a heavy drinker.

36. My whole family has been affected as a result of the infection. It has also affected my family life because I had to give up a well paid job. When we lost my income it was really difficult.

37. I think it is fair to say that I started to feel different about 24 years ago and I put everything down to other things. However it was probably about 18 years after the blood transfusion that my health really started to suffer and I became much worse. I got to the point where I was frightened to tell people how I felt.

38. Once I had the diagnosis I really felt like I wanted to contact everyone at my work and say that I was not going mad and that I genuinely had a medical condition that caused me to have so many heath problems.

Section 6. Treatment/care/support

39. Once I was given the diagnosis I did not have any trouble accessing the relevant treatment. Attending the infectious disease clinic really gave me peace of mind and I felt so reassured when the clinic gave me a telephone number to contact them if I had any concerns or problems. Just having someone to contact made me feel so much better. The clinic have arranged for 6 monthly scans for the rest of my life. I also require regular ultra scans of my liver because of the damage that has been done. At the moment I understand that I am stable but I do not know how long that will last.

40. I do believe that I have now been given all the proper treatment for the HCV and I do not know of any other treatment that might have been available. However I am now very untrusting of the medical profession and I need to see the results of each and every test. If any of my test results are not available or forthcoming I will make sure that I chase so I find out. The diagnosis has given me the confidence to do that because I now know that I have genuine medical complications which are a direct result of me being infected with Hepatititus C.

41. I have suffered a lot of problems with dental treatment in the past and now I appreciate that can be attributed to my HCV. I was under the care of the dental hospital 15 years ago and I am trying to get a referral back to a specialist dental hospital.

42. I feel that generally I am being looked after more and especially with my diabetes. I also feel that my GP is more sympathetic towards me than they had been.

43. I have never been offered any counselling.

Section 7. Financial Assistance

44. I had been claiming PIP and ESA because I am unable to work. Dr Bonnington told me about the Skipton Fund and we completed the application forms. The payment was supposed to take 6 weeks however it took something like 4 and half months as I understand that it took some time to obtain all my medical records.

45. I received a stage one payment from the Skipton Fund of £20,000 in November 2018 and in March 2019 I received the second payment of £50,000. I did receive £333 a month but I cannot quite remember when that stopped and now I receive the Special Category Mechanism payment from EIBSS in the sum of £1,500 a month.

46. I would also like to claim for counselling but I understand that it is quite difficult and a completely separate application.

Section 8. Other Issues

47. I really would like for someone to acknowledge that this whole fiasco has not been handled properly. I would also like someone to be held accountable for what has happened to so many people like me that have been infected with contaminated blood.

48. I also think that I should have been diagnosed so much sooner and that way I would not have had to suffer with so many complications. I have had to suffer with so many other problems and considering my circumstances, access to other services should have been much quicker. It is not that I was staying away from the medical profession but I feel that I have been let down and somewhat cheated. I feel so strongly that I should have been diagnosed much more effectively.

Anonymity, disclosure and redaction

49. I do not wish to remain anonymous. I do not want to give oral evidence.

Statement of Truth

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

Signed..... GRO-C ....

Dated 77/5/19

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

This witness statement has been prepared without the benefit of access to my full medical records. .