Witness Name: Tracey McIloney
Statement No.: WITN2204001
Exhibits: none
Dated: 21st January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF TRACEY MCILONEY

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

I, Tracey McIloney, will say as follows: -

Section 1. Introduction

1. My name is Tracy McIlloney and my date of birth is GRO-C 1969. My address is known to the Inquiry. I do not work and I live with my partner. I intend to speak about my infection of Hepatitis C following a blood transfusion. 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. I believe I was infected with hepatitis C due to a transfusion I received. I would have got this 31 years ago. I did not even know that I'd had a transfusion at the time. I do not believe I was told at the time that I'd had a

transfusion. I knew I had surgery due to the manual removal of my placenta. I knew I was in intensive care. My parents were there and they were both unaware of my transfusion. I had to have this operation as my placenta did not come away as it normally should have. This was all at Bellshill maternity Hospital and I do not know the names of any of my doctors.

3. I found out about my hepatitis C on April 28th, 2016. I had taken not well six months before my diagnosis. I had always been a very active person and trained and did cycling 50 miles a week and ran every night as well and swam. I was into triathlons. I had to stop this training. I was suffering from flulike symptoms but initially I thought I was just getting old and lazy. I was suffering from fatigue and felt tired. I was also vomiting and had reflux. I had sore joints and noticed that my tongue was quite furry. I always felt the cold. I had partially put down my fatigue to everyday living as I have had four children. One was 31, 32, 18 and 21. I'm not one for sitting down so I had to sort of get on with things. I put it down to just having the children. At one stage I had two teenagers and babies to look after. I worked in childcare for a time.

4. I became jaundiced and was sick and losing weight. My urine was quite dark as well. I went on holiday to Malaga and spent the whole time not doing very much. I spent the week in hospital when I came back. This was at Wishaw General. I was kept in for a week before I got my diagnosis from a Dr El-Nujumi. I later went on to sack him as my gastroenterologist. I went for an emergency appointment the morning I came back from Malaga. I was yellow from jaundice and my eyes had gone yellow. I spent a lot of time in Spain so I partially put it down to just having a tan.

5. I was told by Dr El-Nujumi, who said it was probably from the transfusion I had 31 years ago. When he said that he looked a bit like he thought he put his foot in it. He later denied this and I put in a complaint but I took it back because of everything else that was going on and I could not face dealing with it. I recall the Dr El-Nujumi said it could be sexually transmitted and said I should be taken to Monklands hospital that day. I just wanted to get my

head around it. It turns out that my liver was in a sorry state at that point. I did not know this until I saw my medical notes for myself that I had serious liver damage.

6. I think at the time I did not want to find out information, I kept doubting what they were telling me. I've never been a drug user and I'm not a drinker. I tried drinking once and it just did not agree with me. I ended up googling to find more information about hepatitis C and ended up going to hepatitis C support group. This was called at Add Action and they accompanied me to health appointments. This was generally for people with addictions but also they did help people who had contracted hepatitis C. I think part of the issue has being lumped in with drug addicts. I felt like I would have been better treated by medical professionals if I was a drug addict.

7. I felt cast adrift by doctors, I only really told those who needed to know about my hepatitis C that I had it. I didn't tell my partner's family and they were left wondering why I lost so much weight and they don't see me out and about.

8. I had to do my own research to find out about how hepatitis C could be passed on to other people. I was told nothing. I had to look everything up for myself, it was all quite shocking. I just wanted to go out and bury my head in the sand. Because I didn't know about how this could be transferred, I was worried about the children I looked after and I really was just trying to get my head around it.

Section 3. Other Infections

9. I was diagnosed only with hepatitis C.

Section 4. Consent

10. I never had any blood tests in between when I received the transfusion and when I was diagnosed. I only really went to see the doctor with symptoms in relation to hepatitis C but we did not know it was that, at the time. As far

as I know hepatitis C is not a normal part of a blood test. The only time I would have had a blood test otherwise, was when I was pregnant.

Section 5. Impact

11. I generally wasn't coping very well myself. I recall that I saw a hepatologist called Dr McGoldrick who referred me for psychiatric help. I knew I was not ill enough to get treatment in terms of my liver.

12. I suffer from high ANS/APS. These are autoimmune issues and I suffer from rheumatoid arthritis fibromyalgia and extrinsic compression in my stomach. I also have high cholesterol. I believe the high cholesterol can be partially down to tiredness and not eating properly. My dad and my brother both died of congenital heart disease in late 2015. I am now on statins to lower my cholesterol. I'm back to exercise but nothing high impact. Doctors have never officially linked my conditions together but I believe they may have been linked, people at my support group all have the same conditions as me. This is from the contaminated blood group but generally I believe I get better help from the English groups than Scottish groups.

13. The treatment I was on is called Mavyret and this was an eight week course of treatment. This was 3 tablets per day. I started this in July 2018. I'll be six months clear on 23rd January 2019. I believe I have another test to be taken.

14. In terms of any obstacles to my treatment I would say that I was told that it would cost £10,000 per treatment and I felt worthless to the NHS at that point. I felt like I was delayed in actually getting the treatment because I was healthy. I don't smoke or drink. My partner Kevin said that if I was an alcoholic, I would have been treated by now. I had 18 months to wait from when I was diagnosed to actually get treatment. I did not have any symptoms that were separate as a result of this treatment. I felt as bad as I had done before.

15. I'm not aware of any other treatments I thought should have been available to me at the time.

16. Dr McGoldrick and her staff at Monklands Hospital having been great with me. My dentist has also been fine they were the first people I told. I recall calling them crying and they said not to worry. They were really reassuring. My dentist is the Sloan dentist in Carfin. They are a great dentist.

17. I do not really have a social life and as such it was not really affected. This has been partially down to the fact, I felt tired and sore. I believe my symptoms prior to my diagnosis stopped me from having more of a social life than I did have. My partner runs marathons and we'd run together. I'm a member of the GRO-C gym and I go swimming to try and release endorphins. I still suffer now from fatigue and tiredness. I get brain fog all the time and it stops me from being able to concentrate. My partner Kevin worried a lot about my memory and worries about it developing into Alzheimer's.

18. In terms of family life, I never went to soccer club or parents night with my children. This is because I suffer from tiredness and fatigue. I was not able to be as involved as I would like to have been. If I went to any sort of family occasions, I would leave them early or just wouldn't go at all. I do feel that perhaps in raising my children, I was less hands-on than I would have been if I was well.

19. My daughter, who was born at the time that I had the transfusion, was Christina McIloney. She committed suicide on the 24th December 2017. She felt that it was all her fault because it was her birth that caused me to receive the transfusion. Part of this is down to the fact that she was bipolar. When she found out about my diagnosis, she started to take drugs and overdosed. She didn't even smoke until I told her I had been infected. Within a couple of months of her starting down that bad path I had to take over care for her children. I kept telling her it wasn't her fault, but she would not listen. I remember her coming into hospital at one point, she said I was so small. I

believe her bipolar made her reaction worse. Normally she was the strong one but she just crumbled. She blamed herself and kept apologising. I kept having to rationalise to her that it was the NHS's fault not hers. She took a diazepam overdose.

20. I am now looking after my daughter's children who are 15, 13, 12 and 10. Their dad does share the parenting with me now though. I do believe her overdose was intentional. I saw her the night before and she was very low. She had expressed wanting to kill herself a couple of times and had tried four months prior, when she did pass away. Some days she could not get out of bed and that was the depressive side of her being bipolar. She had more downs than ups towards the end.

21. In terms of the stigma, I don't tell anyone about my condition. I'm scared of people jumping to conclusions. I'm worried of people being ignorant and not knowing and thinking that I have it because I'm a drug addict. I was also worried at one stage that I could have had HIV or AIDS but quickly realised that this would have manifested itself before then.

22. I recall that my doctor didn't even want to give me a flu jab in 2017, he just said I didn't need it.

23. I do not believe that my condition had any effect on my children's performance in school.

24. I was a childminder up until 2016. In November 2016, I had to give up work due to not feeling well and feeling fatigued.

25. I believe that this has had a huge financial impact on me. I am currently on benefits and recieved PIP and employment support allowance. I have to go for medicals but I can't even stand in the shower to shave my legs. I was never on benefits before and have only been forced to start in the last two years. I am quite worried about my medical coming up in case they don't understand.

26. My other children are John, who was born GRO-C 1987, Jordan who was born on GRO-C 1987 and Dylan who was born on 7th GRO-C 2001. They are all having to look after me. I haven't cooked dinner for two years now. I can stand but my son has stepped up and started doing a lot of cooking. In the past, I would have done cooking in the morning and would often use my slow cooker but I'm generally just too tired to get on with things now. I worked with children with Asperger's syndrome and autism and that was all quite draining in itself. It's galling to think that 31 years went by before my diagnosis.

27. I do believe I have severe liver damage and although I've never had a transplant, I have had biopsies and have to have fibre scans that I had to wait a year for. There's been no monitoring of my liver since they said that I was clear.

Section 6. Treatment/Care/Support

28. I did have some counselling as a result of my daughter dying and that was bereavement counselling. In terms of my hepatitis C, I did not receive any leaflets for this or anything like that. I only found support by myself. The support I found myself has been quite helpful and has included a Facebook support group. If they had offered counselling I would have taken it, I do feel the fact I have not had anything has been an inadequate. They offered support in just very vague terms of you know someone being there to talk to you if you needed it.

Section 7. Financial Assistance

29. I did not receive anything through Skipton or anything from Caxton. I never got anything from the NHS for a long time.

30. Through the new Scottish Infected Blood Support Scheme, I have received a lump sum of £50,000 in the May of 2018. My hepatologist helped fill out this form. This was a very easy process to apply. I didn't even know that English people were treated differently but found this out through this support groups I know. And I receive £1575 per month. This has meant I don't need to work and this is not taxed. These things were backdated to September 2018 so I have received £5300. For some reason they took the heating allowance of it which was £1000. So it would have been £6300 with the heating allowance.

31. I believe these payments are sufficient now that but I think they should be treated the same across all countries. I do not believe I should have to fight for benefits that are due to me.

Section 8. Other Issues

32. I believe that the Penrose Inquiry was a total whitewash. The NHS should have written to tell anyone who has had a transfusion they should get tested. My ex-partner died of viruses and I am worried that it could have been down to me infecting him. I won't know now because he's already dead.

Statement of Truth

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

Signed GRO-C

Dated May 22, 2020