Witness Name: Sandra Martin

Statement No.: WITN2193001

Exhibits: WITN2193002-005

Dated: 19th October 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SANDRA MARTIN

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

I, Sandra Martin, will say as follows: -

Section 1. Introduction

1. My name is Sandra Martin. My date of birth is the GRO-C 1948. My address is known to the Inquiry. I am single. I intend to speak about being infected with infected blood by means of transfusion in October 1984 that resulted in me contracting hepatitis C. In particular, the nature of my illness, how the illness

affected me, the treatment I received and the impact it had on me. I do not wish to be anonymous for this statement or inquiry.

Section 2. How Infected

2. I had two operations in October 1984 at Princes Risborough Hospital in Buckinghamshire a week apart. I do not wish to discuss the nature of these operations. The operations took place in a private hospital. The surgeon that performed the operation was called Doctor Bruce Bailey. I had general anaesthetic for both the operations. I received blood transfusions following the first operation and during the intervening period before the next operation. I received more than two units of blood during my hospital stay.

3. At no time was I ever informed by Doctor Bailey that there was a risk of being infected through contaminated blood. I assume he didn't know himself that there was a risk.

4. My symptoms progressed downhill from there and overtime I became very ill. Initially, when I became unwell, I was very weak with nausea, vomiting, diarrhoea and a definite loss in cognitive abilities. The diarrohea and vomiting into 1989. The loss of cognitive abilities has remained. Eventually, my symptons worsened and I also suffered from night sweats, sleep apnoea, intermittent fevers and severe headaches and weight loss of over three stone. I was unable to continue in my job. My second GP of that time, (having had to change my first) advised Doctor Mendel to send me for various tests and organised for me to attend Doctor Goldmeier, St Marys, Paddington, London. I had various tests

done most of which were then carried out at the West Middlesex Hospital. No hospital now seems to have my notes. The only letterI have from that time is a letter from Dr Goldmeier to Doctor Mendel asking that I be tested for HIV following post transfusion in 1984. I produce a copy of this letter in evidence and refer to it as **WITN2193002**. The entry identifies that this test was for HIV, which thankfully I did not have. I don't think Hepatitis C was an option to be tested for then as a possible reason for me being ill.

5. Over time, my symptoms transitioned into what doctors labelled as being, Myalgic Encephlomyelitis (ME). I wrote an article that was published in the M.E. associated magazine in March 1998. This article fully explains my symptoms. I produce a copy of this article in evidence and refer to it as **WITN2193003**. My cognitive abilities have never recovered in full. I have never been the same again. They diagnosed me as having ME from a post viral infection, but they didn't know what the viral infection was. Time moved on and in 1996 I read an article which said that a lot of people are misdiagnosed with ME when they actually have Hepatitis C. Everything fell into place, the reason that I was so ill after the blood transfusion, the strange diagnosis of ME with an unknown viral infection that never went away. I remember thinking, 'This is it, it is Hepatitis C that has caused me all these problems through the years; this is the viral cause of the ME'. I went to my GP, Dr Murray who is based at Mackenzie Medical Centre, Richmond Street, Edinburgh. I asked him if I could have a hepatitis C test, and he said, *"No, you're not likely to have this, you don't have the lifestyle to have hepatitis C"*. He did however then agree to do the blood test to set my mind at rest. There is a letter in my medical notes from Doctor Murray explaining

that I had requested a blood test and that it had come back positive for Hepatitis C. There is also reference to me having the operation in Abu-Dhabi this is obviously a mistake by the Doctor as I had the operation in Buckinghamshire. It also states in the letter that I had three livor biopsies in London. This is not true I only had one biopsy in London. The other two were in Australia in 1975 and 1976. Post-op checks ere all normal. I produce this letter in evidence and refer to it as **WITN2193004.** Nobody was more shocked than me when it came back with the results. My PCR was negative, but I had obviously been infected with hepatitis C, I had the antibodies. I am one of the lucky ones who spontaneously cleared the virus. After this, the GP referred me to be observed at the Royal Infirmary Hospital, Edinburgh, for two years to keep a check on things. I was under the care of Doctor Hayes. There is a letter in my medical notes from Doctor Murray referring me to Doctor Hayes. This letter also refers to my multiple blood transfusions in 1984. I produce a copy of this letter in evidence and refer to it as **WITN2193005**. I was mistakenly delighted when my GP initially diagnosed me with hepatitis C, because I thought it could be fixed and I would feel better. I may have spontaneously cleared the virus but I don't know how long it took. I have suffered constant illness since 1984 in which there has been improvement but I have never fully recovered.

6. This was not the case. I was not provided with any further information on the condition. I found out myself. I went online and looked up all the information myself. I don't recall any medical professionals saying very much at all. At that time, I was volunteering (because I couldn't work) at Waverley Care, which is a centre for HIV patients. As I was a nurse, I did have a background in healthcare

that meant I could look into things around the condition. I did tell people like dentists, because at the Royal Infirmary they did say there is a possibility that the virus could reoccur.

7. I have also had a blood transfusion in Australia in 1975 as well, but nothing untoward followed that at all. I also had a blood transfusion in 1993 up in Wick. I had a strangulated bowel and I ended up in hospital requiring an operation in Caithness General Hospital, Wick, for which they gave me a further blood transfusion.

8. I was not given information about the condition. I found this out myself online and using my background as a nurse to find out about the condition.

9. I would have liked to have received information earlier, however I don't believe that the medical profession knew much about Hepatitis C in 1996.

10. The doctors didn't know much about the condition at the time, in an ideal world, a full conversation about the prospects of recovery and treatment would have helped.

11. I was not given any information about the risks of others being infected, I believe because my PCR came back negative. However, in view of the uncertainty of reoccurrence, I should have been given this information.

12. I had to find everything out myself. At the time, nobody knew much at all is how I interpreted all the conversations I had. I wrote to a hepatitis magazine that was based in London and I got a bit of information from there. I don't think even they knew a great deal in 1996. Surprising really, when you think it started so much earlier in the 1970s or 1980s. Nobody knew much, even in 1996.

13. I would have loved it if they had provided me with this diagnosis earlier than when they did. But if the general doctors hadn't been informed about the condition, there was not a lot of information available to provide at that time. There were only things like the article that got me thinking in 1996. People with ME tended to be viewed in a certain way. They tended to say to patients that this is all in the head and they were a wee bit dismissive. I would have loved to have had information earlier but I don't think the information was there. The higher ups may have known about it, but this hadn't been passed down the line I think to the general medical staff. If I had been provided with this information I would have at least understood why I had become so ill and although there was no cure I may have been able to undertake some alleviating steps.

14. It was a shock when I was advised of the diagnosis. Although I had read the article, I had raised this article with my doctor on a 'this might be a bit of a chance' reason and 'I might get better if it is this condition'. My GP, Dr Murray, didn't know anything to tell me. In an ideal world it would have been good not to have to research everything myself and live with the false hope that perhaps there is some course of treatment that might get me through this in 1996. It might have been good to receive an earlier diagnosis; perhaps the previous 12

years I had lived through with so much pain, distress and discomfort were not just something that I had to get through. Nowadays I would expect everyone, GP's everyone, to be able to present to patients' full facts and full support. I felt abandoned, I had a debilitating illness and had to get through it the best way I could.

15. I don't think I was given any information on the risk of others being infected, only because my PCR was negative. I did continue volunteering right up until a few years ago and because of the chances that it could reoccur, I was always very careful. What is worrying is that I was still working as a nurse, when I was at my sickest. Fortunately, I like to think that my hygiene is good. I was careful in my line of work, but it is always at the back of my mind now. I was informed of the risk of reoccurrence but not that I could be at risk of contracting a different strain of hepatitis C.

Section 3. Other Infections

16. There is a large gap in time between infection and diagnosis. I am unsure on which other infections have occurred. I remember that although I was strong, I had no stamina. There were cognitive issues that started during this period and continue to this day. Part of this will be age related, but this has been going on since 1984. I had difficulty with reading, I still have difficulty reading newspapers and magazines. I find this very hard. There is my ME diagnosis but I feel sure this is a consequence of Hepatitis C.

Section 4. Consent

17. No, I don't believe I have been tested since I found out I had this infection. I don't know what they might have done previously.

18. I don't believe I have been treated or tested without giving consent.

19. I don't believe I was tested without being given adequate information. I organised everything myself in terms of getting the tests arranged to gain my diagnosis, they didn't know the information, to give the test to me.

20. I don't know if I have been tested for the purposes of research. Possibly. They may have done so at the Royal Infirmary. I may have even given consent. Sadly, I don't think the scientific world have taken advantage of the people who spontaneously recovered to find out why they spontaneously recovered and why others didn't. I don't know, after all these years, I don't really care, now that there is adequate treatment let them research still.

Section 5. Impact

21. Retaining information for me is difficult. Before 1984 I could review a document, take it all in, take out the key information and go for it. Now I struggle to make sense of simple things. I misread words and mispronounce words. Sleep is another thing I struggle with. Initially I could have slept for Britain and then it transitioned to sleeping badly. In the 1980's, the vomiting and the diarrhoea that I went through, was just dire. It was awful. I lost a lot of weight. I had to crawl up and down stairs, I couldn't move, I couldn't get out and about because when

I did, I collapsed. A number of times I had to get taxis back home from nearby places. Strangers were coming up to me and asking if I was OK. I was however still working. I was sicker than the patients I was sending home. I was working for British Airways as a Nursing Officer. Apparently one of the patients queried to the senior staff, if it was appropriate for me to be working. I was called in by my employer and questioned when that happened, which did not feel good. On my days off I stayed in bed and did nothing else. I would cry going to work and I cried going home. I got zoned in to the idea that I just had to keep plodding on. It was all horrible. I remember that I would get headaches that could last three to five days. I was also spiking a temperature, which would go up a couple days in the week and then go down. During all this, whilst working at British Airways, Heathrow, I was attending a GP but after 6-8 months he eventually diagnosed me as menopausal. I changed my GP, Doctor Mendel then became my GP.

22. When called to the nursing office of British Airways, medical service I was sent home on sick leave, which lasted over six months. On eventually returning to work I started to struggle and Doctor Goldmeier recommended I take a sabbatical.

23. The headaches lasted a couple of years. The spiking temperature could develop at any point. This all led to my ME diagnosis. I was diagnosed with ME at St Marys Hospital, Paddington in 1987. My symptoms mimicked HIV, so I was sent to see Dr Goldmeier. He did a whole raft of investigations but no investigations into Hepatitis C. This possibility was not even brought up. I don't

know the details of these investigations other than there was a large number of them. He did a full check-up in 1987and even checked for STDs. He was pretty clued up and even then the hepatitis C was not brought up as a possibility.

24. Hepatitis C devastated me. This changed my whole life. I was fit, healthy, happy, on a good career path professionally and socially in the midst of it all, financially strong and it just all fell away. I lost my career, my professional standing, my finances, socially I wasn't fit, so even if I had met someone to enter into a relationship with, I wouldn't be up to going out. My whole life changed. I ended up on benefits. That is the most demeaning thing possible. You are disbelieved, you are treated less than nothing by a lot of staff in the Benefits Department. I couldn't work, I did try but I ultimately had to stop nursing. I realised I was a danger as cognitively I could no longer be trusted with medication and physically I was constantly exhausted. This was before I even found out about the hepatitis C. I don't know when I cleared it, I don't know how long I had it for, but my cognitive abilities were in such a poor condition, I realised it was not safe for me to be working. I wasn't fit for anything. I couldn't even clean. I was struggling to clean my own house. The Benefits Department did send me on a rehabilitation course, through a Disability Rehabilitation Officer, but I was struggling with this as well. I was struggling to even get there. Then I developed an erythema nodosum and they then declared me unfit for work. That did make things a little bit easier from this point. There was no more form filling, going through all the hoops and medicals for a time. They did say that I had to keep my mind active and advised me that I had to do a college course to keep busy. I then did a course, three days a week at Stevenson

College, Edinburgh. I managed this by saving up all my energy with constant bed rest and used it travelling to this course and sitting through the class. I would sit there, and then get straight home and go back to bed. I did all the coursework from bed. After the course was complete, I started doing volunteering work which meant I could control the days and hours I attended.

25. I feel like I've never been fully fit for anything since 1984. I've tried to push on which was probably the wrong thing to do. My life could have taken a whole different path really. I could have had a family, if I think about this too much it is pretty devastating. I suppose for myself I think, it was bad enough, however at least I don't have a death sentence. There are those who have developed liver problems and are no longer with us as a result of this disaster.

26. I had a lot of throat infections. Then there is the brain fog, sleeping badly, cognitive problems, general tiredness, exhaustion and weakness that I've had. I've had a lot of falls; my left knee is very seriously damaged now as a result. My right knee is not so good but my left knee is permanently swollen because it has taken the brunt of a lot of the falls. Ive required a leg brace to the left leg and crutches for three of the falls. The ME I developed, I am convinced that is what the hepatitis C transitioned into. I was always fit and active, I try to be now but I am overweight, and its difficult to keep active. I go to yoga and line dancing when I can, but I struggle. I try to go for a walk daily.

27. There was no need for treatment for me as my PCR was negative so I didn't have any of the treatments.

28. Because my PCR was negative, the dentist was happy with that information alone. He does always wear gloves but I am seen any time of the day and not restricted to the last appointment. It didn't affect any other treatment for any other conditions that I can remember. When I form filled, even my GP, didn't seem to think that my diagnosis would affect other care. Medical personnel and benefits people didn't take on board the full effects on my health.

29. I've only got cousins and my aunt in my family and at the time they didn't really understand, I think they thought I was making more of it than I should have. I think now there is more in the news, so my cousins realise there is more going on, but we don't really discuss it. I don't have any close family living with me or a partner.

30. If there was any stigma for me, I just didn't pay it any attention. A lot of people that I know, did have a lot of grief and stigma, but it didn't come to me at all. I found that when I was doing volunteering work, I did tell some people about my diagnosis and the feedback I received was positive and understanding.

31. I have managed getting halfway through doing an Open University degree before I had to stop and I just never took it up again. This was something I was doing to keep my mind active and think about doing something different to nursing. It was an Arts foundation course in 1986-87 and because of my previous training I was advanced two credits. I just couldn't continue with the course. I did complete and pass the foundation course.

32. I had to give up work as a nursing officer with British Airways. I wasn't fit to work in any job. I would space out. I was weak, exhausted and seriously unwell. This caused a huge effect on my finances. I had to drastically alter my way of living. I had put in place certain things with the aim to retire at age 55. One by one, these financial savings had to be disposed of to keep me going until I had nothing left. I sold various bits and pieces, I borrowed from friends and paid them back by selling jewellery and cashing in shares and policies. I would borrow maybe a couple of hundred pounds at a time only because I did not want to get into too much debt. At one point I worked out that my friend's son had more pocket money a week, than I had to live on. That went on until I received DLA later on which helped a lot. It was always a worry though. I would always be worried that I would have to sell my flat. The whole thing was horrendously stressful, awful. I wouldn't wish this on anyone.

Section 6 Treatment/Care/Support

33. I didn't have any support when my health declined from the 80s onwards. I think I did see a nurse at the Royal Infirmary, Edinburgh though after I received the information that I had been infected. I had a few sessions with a nurse, but my cognitive abilities then were a lot worse than they are now which affects how much I can recall. I don't think I found it very helpful as I had found out information myself and the British Liver Association had provided me with some information. Nowadays I would expect that full psychological, financial and emotional support be fully made available to anyone with this diagnosis. I strongly believe that anyone with a Hepatitis C diagnosis should have a clear

path to benefits and not go through the exhausting, traumatising, stressful, benefits process. I remember filling out forms, pages and pages of forms, that would take me a month to complete. It would take me so long I would be receiving letters saying that I had not yet completed the forms and asking where they were. I could only do a little bit at a time. I needed a lot of breaks. Then they would send a doctor to you and he would be at my house for 2 or 3 hours doing the same thing again and again. It was exhausting and worrying. I once had to go through the D.L.A screening twice within 3-4 months.

Section 7. Financial assistance

34. In 1996, when I was diagnosed I didn't really know anything about financial support for hepatitis C. I didn't think I was eligible because I was PCR negative. They did ultimately reject my application. A couple of years later my cousin heard about Frank Maguire at Thompsons Solicitors and suggested that I contact him. I did and he took me on and suggested that I apply to the Skipton Fund. They went through everything and I was turned down because I was a nurse. They reasoned that I probably caught it in my course of employment and they also reasoned that I worked overseas, so I probably got it overseas. However I worked in the nursing office 2-3 years prior to becoming ill and had no contact with patients. My notes are missing too so that was another reason to be rejected as they did not have full notes to review. I remember two weeks after I was turned down, someone in the Skipton Fund embezzled the funds and I thought, yes that was probably why I was turned down. So no, I've had no financial support. I am registered with the Scottish Infected Blood Forum as

another voice. I haven't applied for anything else because I don't think I'll get anything.

35. I have received no financial support at all from any Trust.

36. For the Skipton Fund, I filled out forms, then I had to travel down South to somewhere in England. I cannot remember where they asked me to go. I will be on record.I only knew of the Skipton Fund I didn't know of any other support funds.

37. There were no preconditions that occurred during the application process.

38. I would like to add, for other people who are affected, I think, what they are trying to get is a proper lump sum of money, rather than a yearly amount. Having had to sell things myself, I understand the distress and stress of running short of money. If a lump sum helps settle them and helps them on an even path, then a lump sum it should be. There can never be too much financial assistance, given the worry and stress and upset and the effect on their health and whole lives this has caused. Even after receiving lump sums if they do still need benefits, the lump sum shouldn't be taken into consideration against this.

Section 8. Other Issues

39. I think they need to get to the root cause as to how this all happened. We trusted the NHS and the Government and we were left devastated. Our lives were

ruined. I could have been more productive in society, I could have done more in my job, with my personal life, this was all taken away from me. So much was taken away from so many. They really need to find out the whys and hows in relation to how this happened. The Government did know about the infected blood in the 80s and 70s but chose to ignore it for finances. Why was this? It was easy? Was it that they were not bothered about the outcomes? Perhaps they thought they wouldn't be caught? We need much more investigation.

40. 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. It may be that when I do so, I have something to add to the statement I have given to the Inquiry. I would like to be offered an opportunity to give a supplementary statement to the Inquiry once my medical records have been recovered in full and I have had the opportunity to review them.

Statement of Truth

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

GRO-C

Signed Sandra Martin (Oct 19, 2020 15:16 GMT+1)

Dated Oct 19, 2020