Witness Name: Mary Elizabeth Barr
Statement No: WITN0241001
Exhibits:
Dated: 5 March 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARY ELIZABETH BARR

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 January 2019.

I, Mary Elizabeth Barr, will say as follows: -

Section 1. Introduction

1. My name is name is Mary Barr. My date of birth is GRO-C 1958 and my address is known to the Inquiry. I currently live with my husband with whom I have two children and currently work as a Vicar.

2. I intend to speak about my infection with the Hepatitis C Virus ("HCV"), which I contracted as a result of an infected blood transfusion I received immediately after giving birth to my daughter.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it has had on my life and the lives of my family.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement.

Section 2. How Infected

5. I was infected with HCV on 18-19 January 1991 following my first and only blood transfusion (to date), due to a post-natal haemorrhage at the Rosie Maternity Unit of Addenbrooke's Hospital in Cambridge. I believe that I required around three units of blood.

6. No doctor, nurse or mid-wife offered to discuss the reason for my post-natal haemorrhage which occurred a few moments after the birth of my first child. I had been anxious during my pregnancy that I was becoming anaemic but the GP and others responsible for my anti-natal care refused to put me on an iron supplement or do an extra blood test to check for anaemia. They waited for the date of the routine test which showed that I was indeed anaemic. I started taking iron but because I was diagnosed so late in my pregnancy, it was too late for iron tablets to take effect. I do not know whether the fact that I was anaemic contributed towards the haemorrhage but it probably was a factor in the decision to give me a transfusion.

7. After the delivery, I was taken back into a room where I passed out due to the loss of blood. Following examination, I was told that I required a blood transfusion. I was already feeling awful. I asked the attending nurse if there was a possibility of catching an infection during the blood transfusion, or if the blood had been screened, as I had previously heard of people being infected with HIV following medical procedures. I was told point blank that there was nothing to worry about as all blood was now carefully screened.

8. Initially, after the transfusion I did start to feel better but after a couple of weeks I became incredibly fatigued. Other people I knew who had children, around a similar time all started to feel better but I was feeling

worse and my condition continued to deteriorate. Around five weeks after the transfusion I became severely unwell. In some ways this was good, as I know HCV can take a long time to show its symptoms.

9. On 27 February 1991, My General Practitioner ("GP"), Dr. J Owen referred me along with my five-week-old daughter for tests to Addenbrookes Hospital where we were placed in an isolation unit. This was awful time. I recall my daughter was placed in a kind of crate out of my reach which made it difficult at the time as I was breast feeding her. I recall that one Junior Doctor stood at the foot of my hospital bed and actually joked with her colleague about whether my breast-milk was as yellow as the rest of me. I underwent a series of examinations including: a liver scan and many different blood, urine and stool tests. Dr. Wilks and a consultant called Dr. Rubenstein mainly conducted these examinations.

10. I was told that I did not have Hepatitis A or Hepatitis B but that my liver function was severely impaired. I was also told that this was probably caused by an unknown virus which might never be specifically identified but that I would have to be monitored at visits to out-patient clinics and by my GP. I expressed the great anxiety that this caused my husband and I, not least about the possible risks to the health of my breast-feeding baby. By the end of September 1991, I started to feel better within myself but still had no energy and was emotionally and mentally drained.

11. During this same month I received a letter from Dr. Wilks saying that the hospital had the results of my latest blood test. He told me that we should meet sooner than planned to discuss said results. I found this brief letter incredibly ominous and distressing, particularly as I still felt unwell and fatigued.

12. At the rearranged appointment, Dr. Wilks was not present; only Dr. Rubenstein saw me. Dr. Rubenstein informed me that my blood test results indicated that I had contracted HCV. He told me that he could not

state in any great detail what the implications were and that I should make an appointment with the Hepatologist.

13. In November 1991, Dr. Graeme Alexander, the consultant Hepatologist at Addenbrooke's Hospital saw me for the first time. I mentioned to him that I had in the past asked several of my doctors if there could be any link between the transfusion and my illness. I told Dr Alexander that previous doctors had said no, they could not tell this was the case, and that they could not trace where the donor blood had come from. He expressed surprise that other doctors had brushed the link aside and told me that I must continue to be monitored and kept a close eye on. He also informed me that it was difficult to predict what course my illness would take.

14. Following the appointment, Dr. Alexander sent me literature and leaflets detailing the HCV. This information warned about the probable need for a liver transplant, the end stages of the disease and the likelihood of an early death. This was all extremely distressing. Dr. Alexander also said he was worried about sexual transmission and the possibility of transmission through breast milk to my baby. The warning that I may have put my baby at serious risk of harm, having already breast-fed her for several months caused me a great deal of further anxiety. Dr Alexander also warned me against mentioning my infection to my family and friends as they might think it was similar to HIV and worry they could catch it through something as simple as a handshake. He even advised me not to share hairbrushes.

15. Inevitably, this adversely affected my intimate relationship with my husband. All I received from the hospital were the brutal and bare facts but no supportive information on how to cope with the infection. Most of the information about the disease centred on the worse case scenarios, along the same lines as people who had HIV. I was told blood contact was extremely risky which led to me being overly cautious, so much so that I would refuse to let anyone put a plaster on me if I cut myself; I would do it myself. As time went on I was increasingly surprised at the lack of knowledge displayed by nurses and doctors.

16. In the summer of 1992, my family moved away from Cambridge. The responsibility for my on-going monitoring was transferred from Addenbrooke's to the Royal Devon and Exeter hospital. In November 1992 Mr. T K Daneshmend saw me for my check-up. I found his manner very unpleasant and unhelpful, particularly in light of the fact that at this time, I was pregnant with my second child. Mr. Daneshmend said it was risky and that he would need me to have regular blood tests, breast milk tests along with an umbilical cord test as soon as the baby was born, to try to establish whether or not I had transmitted the virus.

17. During this second pregnancy, I insisted that the doctor regularly test my anaemia levels, as I did not want the same problems that occurred during my first pregnancy and delivery. I took iron tablets when prescribed. My baby was apparently healthy, but I was still required to sit with a breast pump to give samples. I recall the nurses saying that the hospital did not know what to do with the samples and that the nurse's themselves barely knew anything about the HCV virus or its implications. The impression I got was that the doctors and nurses did not want to think about it. Once again, I felt messed around by the NHS. The hospital staff failed to provide any information to my GP and it seemed nobody knew what was going on with my monitoring. More than 6 months later I had still not been told the results of the hospital's tests concerning myself and my baby. Nor was there any word from Mr Daneshmend, or anyone else, about the regular check-ups I had previously been told I should have.

18. My GP at the time, Dr P Hunt attempted on numerous occasions to contact the hospital but to no avail. After many repeated attempts for further information or updates on my test results, I myself wrote to Dr Alexander back in Cambridge to ask what I should do next. My letter to him was apparently "mislaid". After several telephone calls to Addenbrooke's Hospital, I sent another letter to Dr Alexander and finally received a reply from him dated 29 December 1993. This letter told me to ask my GP to find someone appropriate to do the necessary tests locally.

Once again, I asked my GP to pursue the matter. Finally, in March 1994, I was transferred to the care of Dr John Lowes, a consultant at Torbay Hospital.

19. GRO-C

GRO-C In light of the fact that my most recent blood results had shown that I was Polymerase Chain Reaction ("PCR") positive, it was arranged that I would undergo a further scan and a liver biopsy.

20. After my family had moved from GRO-C to GRO-C in the autumn of 1997, I was transferred first to the oversight of Professor E. Elias, at the Birmingham Liver Clinic and then to Dr. Alistair Miller at Worcestershire Hospital. I had further examinations and blood tests, and in the autumn of 2002, Dr. Miller told me the news that my levels of HCV were very low and that it looked like my body was clear of the virus. He informed me that whilst I should not donate blood, I should not be bothered in a serious way moving forward.

21. Whilst I was extremely grateful to receive this news, it could not undo the effects of ten years of the extreme anxiety and deep distress that I had been subjected to, nor the anger that I felt at the unnecessary suffering brought by the NHS upon my family and myself.

22. In the overlap between Torquay and Worcestershire doctors were looking at the treatment with interferon. However, I had read that the side effects were terrible and that there was no guarantee it would work. At this time, it was felt that on balance I should wait to see whether my condition would improve. Consequently, I never received any treatment.

23. Now, thankfully, many years on I am physically all right. Every 2 years my liver is checked or, if I feel unwell, I am told that I should have a liver function test. I was told that there is some light scarring on my liver but that there was evidence of my liver rejuvenating.

Section 3. Other Infections

24. I do not believe that I have contracted any infection other than HCV as a result of being given an infected transfusion. However, I do believe that as a result of my infection I have suffered from a series of mental and physical problems, which have severely impacted my life and the lives of my family.

Section 4. Consent

25. I have been asked if I believe I have been treated or tested without my knowledge or consent and the answer is no, in the first instance I have always consented to being treated and tested.

26. However, I do believe that I was not given adequate information about the potential risk of infection, associated with my blood transfusion. In fact, I was given no warning whatsoever about the risk of contracting Hepatitis C (or anything else) from a blood transfusion. On the contrary. Since I keep a daily journal I have a record that before I consented to receive a transfusion a nurse said that I need have no worries about 'contracting HIV/AIDS or Hep. B or any other "nasties" since all blood is now thoroughly screened'. Another nurse said "Don't worry about having a blood transfusion – it will make a new woman of you". Nothing was ever mentioned about the existence of the Hepatitis C virus. Had I been given the slightest idea of the risk involved and given a choice I would far rather have felt 'run down' or unwell for months than have the transfusion, as I am sure that having a transfusion was not 'life-saving' in my case but more of a 'short-cut' to a return to full strength. But I was unable to make informed consent as I was specifically told that there were no risks of

infections associated with my transfusion, even though I had enquired about potential risk prior to the procedure. I was entitled to believe what I was told but in the end my suspicions were correct, as I ended up contracting HCV. Even after this, when I often questioned whether my feeling unwell could be linked to my original transfusion, my concerns were dismissed by the medical practitioners.

27. The information initially provided to me about HCV made me believe that I only had a short period to live; I had two young children and could not bear the thought of this. Somebody should have told me that I had the chance of clearing the virus and that although my fears were rationale, there were ways of managing the infection.

28. After I was diagnosed, I was told that the doctors were not looking into re-investigating the infected batch. I felt angry and confused that an organisation that was supposed to keep people healthy did not seem interested in preventing infection. They told me the transfusion would make me feel better but it ended up doing the opposite. If I had been told earlier of the risks I might have said no the transfusion. Moreover, I could have been prescribed iron tablets earlier as in my second pregnancy, to reduce the risk of having a haemorrhage.

29. The implications of my transfusion and the subsequent effects of being infected with HCV are not something that I had consented to.

Section 5. Impact

30. The physical and mental effects of being infected with HCV had and still have a profound effect on my life. The predominant physical symptoms at the time after my transfusion were: extreme itchiness, acute pain in my liver area, total exhaustion, dark coloured urine and pale coloured stools, nausea, loss of apatite, a raised temperature and severe jaundice. These were extremely hard to manage and caused me, to say the least, great discomfort.

31. The mental effects took a severe turn for the worse after I had watched the BBC Panorama Documentary: '*Bad Blood*'. I realised my transfusion took place within that window when it was known that there was an infection risk but there was still a failure to screen the blood in Britain in spite of the fact that screening tests were available and already being used in other countries. I was in a time-frame where I need not have been given a contaminated transfusion. I realised I had been lied to; I had asked about it and been told there was no link which was untrue. The BBC programme revealed certain *'cover-up'* attempts. All of this pushed me towards an emotional breakdown; I was in a state of personal crisis. I suffered from panic attacks, insomnia and other unpleasant mental and physical symptoms. My GP at the time had to prescribe me tranquillisers.

32. At this point, in other circumstances, my husband and I would have been trying for a third child, but I was having a liver biopsy and worrying about the effects on my health and the well-being of my youngest child. This stopped me from having a third pregnancy. It had also caused me to shorten the time breastfeeding my babies, because as soon as there was a sign of teeth growing I became worried about the possibility of biting and subsequent bleeding, which could lead to my daughters contracting HCV. Thankfully they were clear. However, this physical and mental trauma, all caused by this virus, ended all hopes of having a third child.

33. For me the on-going consequences are the blood tests and the worry over whether my HCV will flare up. There are lasting mental side effects of having lived with a death sentence for effectively 10 years. Looking back I missed part of the enjoyment of my children growing up. The fact that I had a mental breakdown in the middle of it all made me feel like I was failing my children. My eldest daughter in particular suffered as a consequence. At the time she was very vulnerable and impressionable. I was an emotional wreck. She still tells me *'mum you told me you thought you were going to die'*, and tells me how frightening this was. I did not have the emotional resilience to deal with her doing what normal children

do. I would overreact and she would see me lying on the floor, shaking with a panic attack. She was only aged of 4 or 5 and this greatly affected our relationship. For a long time, she thought I exaggerated how I felt and that I was a hypochondriac. Now she knows about the inquiry and can understand the impact of the physical effects on my mental well-being. At the time however, she could not be aware of that at all.

34. My eldest daughter also went through a phase of GRO-C and I feel that her witnessing my attacks possibly influenced her in some way. My mental state deprived me of some of the enjoyment of being with my children. I recall, for example, a family outing to a theme park, it should have been a happy day, but was ruined when I had a sudden panic attack. I started to feel drained of energy and kept thinking I was going to die. I was living with the thought that the HCV was going to resurge and felt like I could die at any time. I was looking at medical dictionaries and finding out what I could. The dictionaries kept telling me it was a silent killer. Anything I found out was the bad end of the scenario, which all increased my fears of an early death. I try to say to myself that this process has made me treasure my relationship with my family. yet what has happened to my family and me is a very painful thing that I would not wish on anyone.

35. My fears and anxiety along with the constant monitoring continually impacted on my mental health. Now and then doctors would ask me questions which would triggered panic. I remember one time, the consultant Prof. Elias asked me if I had any strange blotches. I immediately started looking for them and worrying about their possible appearance., The same happened with joint pains: the slightest ache brought worry and trepidation.

36. If I have to visit the hospital or change dentist, I have to fill out the forms and put my infected status. Due to this, I have at times felt a "backing off" but mostly I feel people take the necessary precautions such as putting on gloves. The problems with the forms are that I am already anxious, and then I have to explain how and why I got my infection.

37. In the past with other medical procedures, I have been asked if I would have another transfusion and I have been left a quivering wreck. I am anxious about being in hospital anyway but this makes things worse. When doctors tell me the risks of complications are small and I know the risks are very small but because I now have this trust issue, I am forced to go down a path that other people might not have to. This is because I have got something from a small risk: I contracted HCV from a blood transfusion. I just try to be grateful that I am still healthy, but there is still a residual anger. Recently, I have fractured my right shoulder and this has caused a resurgence of my panic attacks about hospital and medical procedures.

38. In terms of stigma, I have always resented the fact that doctors have always questioned the way I was infected. Their denials that it could have been the blood transfusion and that I must have contracted it some other way. I would like it to be known that I have never had any previous operations or transfusions, or immunisation against Hepatitis B. I have never injected myself with drugs, nor suffered any needle-stick incidents or had any tattoos. I have only ever had sexual intercourse with my husband, who is not HCV positive, as shown by tests after my diagnosed infection.

39. I was also asked when diagnosed if I had been near water with rats. After giving birth, I was told to go for a swim when I was not feeling well and this made me wonder if the indoor pool I used did have a rat infestation and could have been the reason? All of these theories were to digress from the point that I simply, must have contracted HCV from my blood transfusion.

40. I was told by medical professionals not to tell other people about my HCV infection, so I have told very few people voluntarily (with the exception of statements on medical forms). I was told for example, not to tell my children's friends parents, as they might not want sleepovers. I found this awful. Some of the counselling (which I had to seek privately) re-enforced this. Due this this I told only my immediate family who have been

incredibly supportive. My father, also a priest, has helped tremendously; he helped me to re-connect with my husband and made me feel like I was a real person again.

41. My infection with HCV has also had a major impact upon my career. I could not go back to work as a Vicar whilst I was suffering with a mental breakdown. If had not been for this I might have progressed further through the church. I was very ambitious and have a doctorate in Theology and Philosophy. I wrote a book that was published about whether women should be ordained into the priesthood; this was then used in debates. I worked on commissions for bishops and I would have liked to serve in the higher office, but I could not progress because of my illness and the associated problems. In some ways it was positive as I formed greater relationships with my family, as I was happy and thankful to be alive and able to spend time with them. I have subsequently returned to full time work but there were problems explaining to employers the gap in my Curriculum Vitae, where I was required to have time off work.

42. My infection with HCV has also impacted me financially due to the loss of employment. The period in which I could not work meant I was not earning money; this was a stressful situation to be under with two small children and their attendant costs along with the upkeep and daily running of a family home.

43. My infection also had an impact on my husband's career. He was running a separate parish. It certainly affected him emotionally and mentally, we both had to seek help. It definitely affected his job, thinking about the children and me; it has a knock on effect on every aspect of your life. When we lived in GRO-C it impacted on his ability to function work wise. He could not articulate what the problem was as we'd been advised not to discuss my infection with anyone. It caused people to wonder what was going on. Due to the fact that we could not explain, inevitably, especially in a church situation, people speculated (and drew false conclusions) about the reasons for our times of obvious distress.

44. The infection in its first stage had far reaching consequences; it affected all relationships within my family for some time.

Section 6. Treatment/Care/Support

45. I do feel as though I have faced difficulties in obtaining answers to questions about my HCV infection.

46. In the past, I had to face further obstacles in pursuing legal action. I was deemed *'well enough'*, so nobody wanted to pursue legal action in my case unless I paid, which I could not afford to do. At this time there was no legal aid available for my case.

47. As a result of the Panorama documentary, I contacted a legal representative at the solicitor's firm Deas Mallen Souter who told me that "there is no form of compensation for those that have contracted Hepatitis". She encouraged me to write to my local MP, (which I did) particularly on behalf of haemophiliac victims of HCV infection in order to raise public awareness and sympathy for all sufferers. In one of her letters to me, Karen Thompson of Deas Mallen Souter wrote: "Public awareness and sympathy can only help in urging the government to pay some form of compensation" Quite apart from the issue of compensation, I also wrote to the MP and the Director of Public Health for South and West Devon in regards to treatment, in particular, the Interferon treatment. I remember that there was a question of whether this should be provided by the National Health Service (NHS), as it could be too expensive. I found this question to be very damming. In part the problems were caused by the NHS, so the treatment should be made available free of charge. I did not receive any helpful responses from MPs or the Director of Public Health.

48. In regards to psychological support, this was never offered to me. Due to my mental state at the time I decided to make private arrangements for

counselling. I found this difficult as no one fully understood. One counsellor was doing therapy for people with aids and put me in the same bracket. This only exacerbated my anxiety. Much of my time at this stage was spent inquiring into organisations, which could help me with my mental health.

49. I found the process of looking for counselling awful, it was not something I should have had to do. When I asked my doctors about counselling the implication was to not make a fuss but to get on with my life and that I did not need anything other than the factual information I had been given. It was made clear that there were no provisions for such help for people like me. I was told to be glad that I am not like other HCV infected people who were already dead or dying of the disease. Of course, I was glad that I was not in worse condition but I still needed my own help.

50. I recall a time after the BBC Panorama Documentary *'Bad Blood'* came out, there was a helpline and I remember ringing that number. I never got through; it was always an automated message. I remember thinking at the time that I should be able to speak to someone. For me it was worse that I had made the choice to contact someone and ask for help only to be met with nothing but an automated message and nobody to speak to. The helpline was there to provide help, not leave you feeling suicidal.

51. I can confirm that during my interview with the inquiry, I have been informed about the access to the support mechanism that the British Red Cross provide.

Section 7. Financial Assistance

52. Eventually I discovered the existence of the Skipton fund and through this I registered for the ex-gratia payment scheme for people 'inadvertently infected with Hepatitis C' as a result of NHS treatment with blood or blood products. I applied for this and in December 2004, having filled in numerous forms and obtained medical evidence of my infection I was

awarded the Stage 1 payment, which equated to £20,000. I gave part of this money to my sister as she gave up her time to look after my baby while I was very unwell as a result of HCV and some of the money paid for my counselling. Through the Skipton Fund I also receive a fuel allowance annually and a regular annual 'Stage 1' payment. I try to not to think about these payments as it makes me relive the reasons as to why I am receiving said payments.

53. The very distressing issues I encountered with the financial process was having to trawl back through all my journals, notes and large Hep. C correspondence file for 'evidence' to document for the Skipton Fund and to go to my GP to ask for proof of blood tests; it was all down to me. I was still at the stage where having to think about the process was not helping my mental state at all. To me it seemed like it was all there in my medical records; why could they not just look through them and sort it out; why do I have to try and fight this out? Why can my doctors not access the information they need to assist in my application. I should not have to fight this battle.

54. I also remember at one point thinking because I was functioning and back at work earning, that I was going to be asked to repay the compensation, as I was no longer in a bad state of health. There was something about the compensation that made it seem like it was only for the very seriously ill. I felt like the emotional and mental dimension of it all and the breakdown that I experienced had a residual effect on me that has, to this day, not been taken fully into account. What I have had to contend with is not insignificant and I do not feel that people have taken this on board. I feel as though nothing can compensate for the unnecessary suffering brought upon me and my family. Not to mention those whose plight has been more serious, even fatal, as a direct consequence of being given a contaminated blood transfusion. I was in the window where something could have been done to prevent the infection and this frustrates me even further.

Section 8. Other Issues

55. I would like the inquiry to know that it churns my stomach up thinking about what has happened. I recorded the BBC Panorama Documentary and I hid it. Any communication I receive, I file it away and do not look at it further. It pains me to see what has gone on and only re-surfaces hurtful memories.

56. One of the biggest things is the need for public acknowledgement that wrong was done, to admit there was a cover up and that people did not attempt to answer for what had happened when they should have done. It is somehow putting a marker on that, which feels really important.

57. If I could go back in time and not have the blood transfusion I would do that. I am still living with the emotional and mental consequences of what happened. I am grateful it is not worse in my case, but I am resentful that it occurred in the first place. The news and the inquiry bring all of my partly repressed, - because you can never completely submerge them – painful thoughts and feelings back to the surface. However, I believe It is important I go through all of this for my own benefit and for the benefit for those people who cannot now speak for themselves. Somebody needs to put their hand up and admit that this was a horrendous mistake. Somebody must take the necessary consequences for what has happened.

Statement of Truth

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

Signed GRO-C

Dated 21/iii/19