Witness Name: J Wheatley
Statement No: WITN1601001
Exhibits: 0
Dated: April 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOYCE WHEATLEY

I, Joyce Wheatley, will say as follows:-

Section 1. Introduction

1. My name is Joyce Wheatley. I was born on GRO-C 1960. I live at GRO-C GRO-C Staffordshire, GRO-C

2. My late husband, Stephen Peter Royle, (born on GRO-C 1957), was infected with Hepatitis C through contaminated Factor VIII concentrates. He died on GRO-C 2009, aged 51, having developed end stage liver cirrhosis (to include oesophageal varices and ascites) and metastatic liver cancer.

3. My daughter, Samantha Shaw, has also provided a witness statement to the Inquiry under **WITN1802001.**

4. **This witness statement has been prepared without the benefit of access to my husband's full medical records.**

Section 2. How Affected

5. My husband had mild Haemophilia A. He was initially treated at the Manchester Royal Infirmary (MRI) under the care of Professor Hay. After we moved to North Wales in 1993, he was treated at the Glan Clwyd Hospital (GCH) under the care of Dr Craig.

6. He was initially treated with Fresh Frozen Plasma (FFP) and Cryoprecipitate before moving to Factor VIII concentrates when these became available.

7. I specifically recall my husband being given large quantities of Factor VIII concentrates following an accident in 1982. He fell off a ladder and broke his hip which necessitated daily injections of Factor VIII concentrates for a week.

8. My husband received no warning in relation to the risk of infection from the use of Factor VIII concentrates; which were instead described to him as a "*wonder drug*".

9. My husband was infected with Hepatitis C via contaminated Factor VIII concentrates.

10. I remember receiving a furious telephone call from him in or around 1983 whilst I was at work; which was about 12 months after he had fallen off the ladder. He said that he had received a letter from the MRI which stated that there was a chance he had been infected with Non-A Non-B Hepatitis as it was then known (Hepatitis C) having possibly received a contaminated batch of Factor VIII concentrates. The letter also contained a list of things which my husband was not to do which included donating blood, having unprotected sex and sharing toothbrushes, razors and the like. My husband was extremely angry that the letter had been sent to him via the normal post due to the highly sensitive subject matter which it concerned.

11. My husband went storming off to the MRI where he was asked a number of searching questions to include whether he had recently been poorly and/or

whether he had felt ill or suffered with any side effects after receiving Factor VIII concentrates. He was specifically asked whether he had suffered any flu-like symptoms. He had not suffered with any of the above and answered to this effect. Upon hearing this, the clinicians told him "*not to worry and that you have been one of the lucky ones*". They told him that he would be fine and to forget about the letter he had received. They did not conduct any tests on him and sent him on his way. I do not know which clinician(s) my husband spoke to on that day.

12. Time passed and we both forgot about the letter and moved on with our lives. We went on to have two wonderful children before moving to North Wales in 1993.

13. In or around 1995 my son was having some tests done at the GCH in readiness for his adenoidectomy. Dr Craig wanted to test my son's blood prior to the surgery to ascertain whether he had any clotting issues. The tests were carried out and Dr Craig ascertained that my son had mild Von Willebrand's Disease (VWD).

14. Dr Craig therefore tested my husband and me to confirm where the VWD had come from. It turned out that I also had VWD. The tests also confirmed that my husband had Haemophilia and, shockingly, Hepatitis C. The test results were read out to us and in respect of my husband Dr Craig said to us "*He has Haemophilia and of course Hepatitis C*". This was how we found out that my husband had been infected with Hepatitis C. Dr Craig assumed that we were already fully aware of the Hepatitis C diagnosis because it had apparently been documented by the MRI in my husband's medical records (I have unsuccessfully tried to get hold of these); but no one had ever told us about this. It was frightening to think that something so serious was recorded in my husband's medical records yet we were never told about it.

15. Dr Craig was absolutely mortified and, to make matters worse, she had undertaken her medical training with Professor Hay. She apologised profusely that we had found out in such a terrible way at a routine appointment. I do not blame Dr Craig in anyway as she had no idea that we

were unaware of this diagnosis. She then explained Hepatitis C to us by likening it to a "*ticking time bomb*". She told us that all of our family would need to be tested and thankfully our test results confirmed that we had not been infected with Hepatitis C.

16. When we first moved to North Wales, I remember asking clinicians at the MRI whether my husband's care could be transferred to the GCH but they initially refused this request. Looking back, I wonder whether their reluctance was due to the fact that we may have found out what was in the medical records if my husband's care was moved to another hospital. Of course, this was exactly what happened as referred to earlier in my witness statement.

Section 3. Other Infections

17. My husband received several letters regarding the fact that he had been put at risk of vCJD.

Section 4. Consent

18. My husband was tested for Hepatitis C without his knowledge and therefore without his consent.

19. I also recall Dr. Craig mentioning to us at some point that "*Stephen had avoided HIV*" so I presume that this was recorded in his medical records which would suggest that he was also tested for HIV without his knowledge or consent.

20. I believe that my husband was used for the purposes of research without his knowledge or consent. He would have been relatively easy to track because he only had mild Haemophilia which meant he received Factor VIII concentrates on relatively limited occasions.

Section 5. Impact

21. Unbeknown to my husband, he had been living with the Hepatitis C Virus in his system for many years.

22. My husband was a Domestic Appliance Engineer, working for Electrolux. He was afforded the opportunity to start his own business in North Wales (in partnership with two others), working under the umbrella of Electrolux. This was what prompted our move to North Wales in 1993. Things were going really well with the business and life was good.

23. However, about three years later, in or around 1996, my husband started to suffer with fatigue. He used to get in from work at 5pm and be asleep on the sofa by 6pm. He was always absolutely shattered. The fatigue was far worse than a severe tiredness; it was all encompassing and totally floored my husband.

24. His job was a strenuous one and it was abundantly clear that as the fatigue worsened, my poor husband's ability to carry out his work was severely compromised. In the end he had to give up work and we therefore lost the business which had a terrible financial impact on us. When my husband had started the business he had signed a contract with Electrolux which prevented him selling his part of the business in the event that he left. The contract provided that his part of the business would be shared equally between the two reaming partners so we were left with nothing.

25. Not long after this, my husband suffered a very bad nosebleed as a result of which I telephoned for an ambulance. He was taken to the GCH but I don't think they realised how much blood he had already lost prior to his arrival and subsequent admission. They took him up to the ward and I believe that they had to put cocaine up his nose to stop the bleeding. Whilst he was in hospital, he tried to get up and go to the toilet but slumped to the floor; his

heart had stopped due to the extreme blood loss and he was unconscious. Luckily they managed to resuscitate him.

26. He was taken to theatre the next day. In desperation to stop the bleeding, clinicians packed his mouth with something that had a long string attached to it. However, unbeknown to the clinicians my husband was still bleeding inside his mouth. Sometime later, the clinicians removed the packaging from his mouth and appeared visibly horrified to find out that my husband was still bleeding heavily.

27. The next step which the clinicians at GCH were going to take was to tie an artery to stop the bleeding. My husband was begging them for Factor VIII but they refused to treat him with the same on the grounds that they were not a Haemophilia Centre. He therefore asked them to administer him with FFP but they also refused this request.

28. I remember receiving a telephone call from my very distraught husband pleading with me to get into contact with the MRI to ensure that he was transferred there. He was literally "*scared to death*".

29. I became extremely concerned at this point so I telephoned the Haematology Department at the MRI and spoke to a lady called Olive. She told me that under no circumstances should the GCH tie his artery. She got in touch with clinicians at the GCH and I believe that she told them that if they took this course of action then my husband would bleed to death.

30. Following this intervention by the MRI, my husband again asked to be treated with FFP and the clinicians agreed saying "*what a good idea*", effectively making out that this was a new idea when they had already refused my husband the same.

31. My husband was then moved to a private ward which had biohazard warning signs plastered all over the door. They had obviously cottoned onto the fact that he had Hepatitis C and had been bleeding heavily all over the main ward.

32. When my husband was finally well enough to be discharged from hospital, he emerged as a different man; he was never the same again. His poor health prevented him for undertaking any manual work; which was what he had done for all of his life. He knew that he would have to find a way to work from home and I take my hat off to him as he retrained himself to enable him to earn a living with computers. He went on to secure a job with a US firm who sold server space. This was effectively a firm which was open for twenty four hours per day which afforded my husband the opportunity to work from home.

33. Even though he was working from home his health was still deteriorating. He was exhausted and would have to sleep for a couple of hours every afternoon. The lethargy was very difficult for him to deal with and by this time, he had also started to suffer from brain fog which he had to somehow negotiate his way through. At the time, neither of us had any idea that these symptoms had been caused by his Hepatitis C.

34. I remember my husband attending one of his routine six monthly clinic appointments at the GCH which always involved him having his blood taken. I also recall that he always had a star next to his Liver Function Tests (LFTs). I recall one of the clinicians mentioning something about Interferon treatment which could potentially eradicate Hepatitis C. However, we were told that the treatment was extremely unpleasant and similar to Chemotherapy. They also told us that the treatment came with no guarantees and that you had to have a certain type of Hepatitis C in order for the treatment to have the best chance of working. I remember chatting to my husband about this treatment and he decided that he did not want to go ahead with it because there was no guarantee that it would clear the virus. I don't know whether we were both being ostriches who were burying their heads in the sand but I do know that neither of us had any idea that my husband was so close to the end of his life. Life went on; if you could call it life and we just carried on and before we knew it another few months had passed.

35. I remember my husband having to take a trip to London to meet up with some of the other employees of the US firm that he was working for. I cannot recall

the exact dates, but I think that it was in the summer of 2008. He went for about three of four days. He telephoned me on the day before he was due to come home and told me that he felt absolutely awful and was too unwell to travel home. He was forced to stay in the hotel for an extra night. Somehow he managed to drive home on the following day but he kept having to stop to be sick on the side of the road. When he arrived home he looked dreadful. He did mention to me whether this could have anything to do with his Hepatitis C and liver problems and he also suggested to me that he could have cancer. I said "*it can't be cancer as the tests would have shown this*".

36. My husband's health continued to decline and in or around January 2009 he telephoned me, whilst I was at work, to say that he had been sick and had brought up blood. I remember rushing home from work; which at the time was the local primary school. I took one look at him and took him straight to the GCH. The clinicians put a camera down his oesophagus and told us that it was inflamed and bleeding. They prescribed him some tablets and told him to persevere with these and then sent him on his way again.

37. However, my husband was not getting any better and was experiencing severe pain on an almost daily basis so we returned to the GCH. The clinicians had another look inside his oesophagus, via a camera, and told us that everything was looking good, things were healing up and basically made out that any pain which my husband was complaining of, was in his head.

38. Shortly after this, my husband suffered another severe bleed from his oesophagus and was taken to the GCH via ambulance. He was in an awful state and had blood pouring out of him; I can still smell the blood today. The clinicians told me that he needed to be moved to intensive care but that he was too poorly to be moved anywhere. I remember asking a nurse what was causing all the bleeding. She seemed very reluctant to tell me anything but she did say that the bleeding was coming from his oesophagus and she mentioned oesophageal varices. She then told me that "*it was all part and parcel of his condition*". I remember going home and googling "*oesophageal varices*" and finding out that it was indicative of end stage liver cirrhosis and

was something that my husband was not going to recover from. I felt numb and completely floored.

39. When I returned to the GCH the next day, my husband's stomach had swollen due to a build up of fluid (ascites) and I remember him asking me whether I had looked up what oesophageal varices were but I did not have the heart to tell him what I had actually discovered. Instead, I told him that it meant that he had a few extra veins in his oesophagus.

40. The clinicians sent my husband for a liver scan and I remember them telling us that the scan looked really strange and it looked like the liver was trying to heal itself. There was no mention of liver cirrhosis.

41. My husband kept telling the clinicians that he was in pain but the only thing they gave him was paracetamol. He explained to them that he could not take paracetamol as it was not good for his liver but they refused to give him anything else.

42. I remember one consultant advising us that he had considered the liver scan and that the best course of action would be a liver transplant. However, he said that it was a very risky operation for my husband and that he would have to be transferred to a hospital in Liverpool for the procedure. However, the consultant told us that he would need to ascertain the type of Hepatitis C which my husband had before he could go ahead with the transplant. He told us to go home and think about the information he had given us and make a decision in relation to whether my husband wanted to go ahead with the transplant. He made an appointment for us to return to the GCH in two weeks time.

43. However, during this two week period my husband took a turn for the worse and the clinicians at the GCH had another look inside his oesophagus, via a camera. Usually he would be fine and walking immediately after undergoing this procedure but, on this occasion, he came out in a wheelchair looking extremely poorly. On returning home he tried to work but he was too unwell to do so. He therefore asked the US company if he could have some time off

and they agreed to his request. He spent most of the following week in bed and rarely ventured downstairs.

44. However, one evening he felt a little better and came downstairs to where my daughter and I were watching television. He told us that he was watching a documentary upstairs about the Fritzl case in Austria. He asked us if we wanted to watch it with him and we told him that we would give that programme a miss. He therefore went back upstairs. I felt awful because I knew he was watching it alone on his little television. My daughter and I therefore shouted upstairs and told him to come back down. We all watched the Fritzl programme together on the downstairs television. I am so thankful that we made this decision because later on that evening he started bleeding from his mouth again. We collected the blood in a bowel because often the clinicians at the GCH often failed to appreciate the sheer volume of blood that my husband had lost prior to his arrival at the hospital. My husband went to the hospital via ambulance and I followed behind in the car.

45. My husband was taken to the resuscitation area as the clinicians were not happy with the amount of blood which he had lost. My husband told me to go home to have some sleep before returning with some of his things. He told me that he would telephone me to tell me which ward he had been put on. I had a really bad feeling about everything but I went home and oddly managed to sleep for a short while. When I woke, I was surprised that I had not received any text or missed call from him. I telephoned the GCH and was told that my husband had suffered another bleed which they were struggling to contain and that he was currently in theatre. They promised to call me when he returned from theatre; which they did. I was told that they had had to utilise something similar to a "*balloon*" in order to deal with the bleeding.

46. I was not unduly worried on hearing this information because my sister-in-law, who had previously worked at a hospital, had been advocating the use of this procedure for ages. I actually felt quite relieved because I thought "*finally they had done what she had been suggesting*". I was told that he would be going back to theatre later that day and would then be sedated for twenty four hours to allow his body to recover from the procedures. They said that we

could go and see him but that he would be unaware of our presence. My daughter and I went to see him and I asked the clinicians to telephone me to let me know when they had taken him to theatre.

47. I dropped my daughter off at her workplace and then went home. As expected, I received a telephone call from the hospital to confirm that my husband had been taken to theatre. I therefore went to have a nap. The phone rang at 4.30pm and I asked if he had come out of theatre. The woman who had telephoned told me that a doctor had asked her to call me to request that I come to the hospital to have a word with him. They said that there was no rush but I was told to get there as soon as I could. I asked if everything was okay but she did not really affirmatively reply which was disconcerting in itself.

48. On arrival at the hospital, the doctor asked if I had come on my own. I told them that I had because I had not been told to bring anyone with me. I was directed to a relative's room. I was willing to go but I insisted that I know there and then how my husband was. A nurse told me that everything would be explained to me once I was in the relative's room. However, I would not budge until I knew what had happened to my husband. I asked if he had died and was told that he was still alive. I asked whether I needed to call my children and I was told that I should. I knew at this point that it was really bad news. My son was studying at Manchester University and my daughter was at work. I telephoned my daughter and told her that I did not know what was wrong but that she needed to get to the hospital. She was in bits and I was trying to calm her down. I did not call my son straight away as I thought I would do that once I had been provided with some concrete information.

49. By this point I was already in the relative's room but I was still alone when the doctor came in because my daughter had not yet arrived. The doctor told me that they had encountered difficulties in that they had discovered a large hole in my husband's oesophagus and they were unsure as to how it had come about. The hole meant that they were unable to stop the bleeding and I was told that it was too dangerous to operate. I was told that their plan was to keep

my husband on the ventilator but cease all other treatment and medication. I asked if we were talking days and he said *"no, hours"*.

50. I telephoned my sister who lived close to where my son was residing at University so she was able to collect him and bring him to the hospital where my daughter and I were waiting for them. My husband passed away at 10pm that evening which was 28th March 2009. The coroner said that he did not want the autopsy conducting at the GCH and instead wanted it doing where he was based, which was at a hospital in Wrexham. He also said that there would be an inquest. I remember the undertaker telling me that he could not do anything without a death certificate so the GCH provided me with an interim one.

51. My son and I went to see him in the chapel of rest; my daughter did not want to see him in this way. GRO-B
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52. The funeral went ahead and we had to have my husband cremated because we weren't allowed a burial because of the Hepatitis C. However, my husband would have wanted a cremation so ultimately this choice was not taken from us but it would have been had his wishes been different. The inquest took place a few months later and I remember that there was someone there representing the GCH. I believe that this was because I had raised a complaint about them in relation to the care he received in his final weeks. I had found out that my husband had extensive malignant neoplasm that has spread from his liver to his lungs and to his oesophagus yet despite this, the only painkiller he was offered was paracetamol. They had recorded that my husband had refused pain killers but the only reason he had refused the

paracetamol was because he knew that it would be bad for his liver. He should have been on morphine. I was distraught as he must have been in so much pain.

53. My issue was not that the GCH could have done more to save him because I was aware that this was not possible. However, they could have made him comfortable in his last few weeks and informed the family of the position a lot sooner so that we could have properly prepared for this passing. My son could have come home from University and spend a few weeks with his father and say goodbye properly instead of the few moments he had with he was on a ventilator.

54. The impact upon me of my husband's death was huge. I devastated beyond belief and struggled for a long time. Life as I knew it also changed because if I wanted to keep my job at the local primary school I would have to sell the house because my income was insufficient to pay the mortgage. If I sold the house I would then have to move further away, to a much smaller property, and would have to travel a greater distance to do a job which I loved. If I wanted to keep the house I would have had to seek a better paid full time job. In the end, I felt forced to sell the house.

55. I then met my current partner and moved to Stoke. However, although this was a positive step for me it effectively split the family up. My daughter moved with us but my son decided to remain in Manchester. GRO-B
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56. I know people lose family members but it's something that should never have happened. My husband was only 51 when he died and we had been married since he was 22 and I was 19. I remember saying to him that he couldn't go as I did not even know how to change a plug.

57. It has been only relatively recently that I have started to tell people what really happened to my husband. I was so enraged by how my husband had caught this virus that I felt that I had to tell people the truth. I think my anger just took over. A few people did say "*oh is that because he liked a drink*" which was both infuriating and upsetting. Previously we had not told anyone outside of our family due to the fear of stigma. In fact about 13 months ago I told a close friend what had happened and he said that he was not even aware that my husband had Haemophilia; which also showed how private my husband was.

58. When my daughter gave birth to her son, it was both a joyful and sad occasion. I was naturally overjoyed by the situation but it was also tinged with sadness because my husband should have been there to meet his first grandson.

59. I also lost the person who I had so many shared memories with and in particularly in relation to our children. When my husband died I was consumed with sadness that there was no one else in the world who shared those memories with me. He was cruelly taken from us before his time.

Section 6. Treatment/care/support

60. I refer to paragraphs 31, 51and 52 above.

61. It was virtually impossible for us to obtain any type of life insurance due to my husband's Hepatitis C.

62. Neither my husband nor I were ever offered any counselling or psychological support in consequence of his infection.

Section 7. Financial Assistance

63. The Manor House Group initially put us in touch with the Macfarlane Trust (MFT). We therefore approached the MFT who redirected us to the Skipton Fund (SF) because my husband had not been infected with HIV. The SF gave us some forms to fill in which we did, with the assistance of Dr Craig, and shortly afterwards my husband was awarded the Stage 1 Payment. We used this payment to double glaze the windows in our house.

64. We were aware that a Stage 2 Payment also existed but my husband's medical condition, at the time, was not deemed serious enough for him to be awarded the second payment. However, when my husband was admitted to the GCH towards the latter stages of his life, I remember him asking the consultants whether he now met the criteria for the second payment.

65. The clinicians gave my husband the requisite forms to fill but before the application had been finalised and submitted, my husband passed away. A short while after my husband's death, I remember a consultant informing me that the forms had been signed and submitted which would mean that I would get the money. I was told this news as if it was something really positive and I felt that the consultant was implying that I should not be complaining about the care (or lack of) afforded to my husband.

66. I did receive the Stage 2 Payment but most of it was swallowed up paying for my husband's funeral and I put the rest of it towards the expensive monthly mortgage payments; the latter afforded me some much needed breathing space in order to gather my thoughts after my husband's passing.

67. We never received any grants or loans from the SF.

68. I now receive financial support from EIBSS which includes the annual winter fuel payment. However, I have to fill out a form every twelve months to apply for the money the following year because it is by no means a guaranteed

award. It is therefore difficult to plan in relation to finances because you cannot guarantee that this money will be awarded each year.

69. I remember that the amount I received from EIBSS the second year I applied was less than the figure I received in the first year. At this point, I had to give up work and EIBSS said that I was eligible for Universal Credit (UC). Despite the fact that I was not actually receiving UC, EIBSS deducted the sum they thought that I should be receiving from UC. Luckily, the banding rates changed a short while later so my money went back up to the figure I was awarded in the first year.

Section 8. Other Issues

70. I hope this Inquiry will provide me with satisfactory answers to my many unanswered questions. I also want to know why it has taken so long for us to get to where we are today.

71. I believe that both those infected and affected by this tragedy should be awarded compensation. However, no amount of compensation can bring back my husband; I should still be with him today in our lovely house in North Wales.

Anonymity

72. I do not want to apply for anonymity. I have redacted a portion of section 5 for the reasons stipulated in that section.

73. I do not wish to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 15/05/20