FINAL

Witness Name: Carole Anne HILL
Statement No.: WITN0024002
Exhibits: **WITN0024003/4/6/7.**
Dated: 19 October 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAROLE ANNE HILL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 03 September 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Carole Anne HILL, will say as follows: -

Introduction

1. My name is Carole Anne HILL. My date of birth and address are known to the Inquiry. I am a married woman with two grown up sons, and three late middle-aged stepchildren, who live distantly. I live at home with my GRO-C husband, a retired GP, GRO-C GRO-C GRO-C I intend to speak about my infection with Hepatitis C.

1.1. In particular, I will go into detail on the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family, and our lives together.

How Infected

2. I was infected with Hepatitis C in January 1987 as a result of a five-unit blood transfusion at Cromer Hospital.

Background

2.1. In the 1980s, and indeed before then, I suffered with heavy menstrual blood loss, known as menorrhagia. I had an exploratory procedure at

Chelsea Hospital to see if the heavy bleeding could be explained. My organs were deemed "perfect", and there was no explanation found for my menorrhagia. Various methods of controlling the bleeding, including hormone treatment and orally administered iron, were unsuccessful.

2.2. Consequently, my health deteriorated to the point where my Serum Iron was as low as 6. It was decided that I needed an urgent blood transfusion to replenish my iron supplies. I was almost 43 years' old.

2.3. I do not recall who took the decision that a transfusion was required that day, especially given that when I received my transfusion, there had been particularly heavy snowfall and the routes to the hospital were treacherous and mainly impassable.

2.4. The roads were so bad that a friend with a 4x4 had to drive my husband and me to Cromer Hospital, as our cars were not suitable for the road conditions and the hospital is in an exposed coastal town. Our friend drove my husband home shortly after my admission.

2.5. It was in 1987 I received the transfusion. I was told I would feel 'like a new woman' following my transfusion; 31 years on, I am still waiting for this to happen.

2.6. I do not recall being put to bed, but was told that blood was being flown in by helicopter, due to the treacherous conditions. I began the transfusion on the evening of my admission, but cannot recall with certainty in which arm I received it, but think it was my left arm.

2.7. Very soon after the transfusion began, I experienced terrible shaking and chattering of the teeth (rigor), the likes of which I had only seen in people in shock or acute infection. Two nurses came in to check and confirm that they had administered the correct blood type and, satisfied that they had, left me to wait it out.

2.8. I remember very clearly feeling like I was a rat in a trap: like I was tied to the bed with no escape. This feeling was totally unexpected.

2.9. The transfusion took almost two days to complete. On that first night I put on the radio, which, coincidentally, was at one point airing a programme on Radio4 about transmissible diseases, such as HIV, via blood transfusion.

2.10. None of the medical staff at Cromer provided me with any information or advice about the risk of infection prior to my receiving the transfusion.

2.11. In May 1987 I had a partial hysterectomy at the Norfolk and Norwich Hospital, and, at my request, my ovaries were left in situ. A few weeks after this operation, I received a letter noting an abnormality in my blood test and requesting me to take another, which I did, which was also irregular but not pursued. These abnormalities became something of a regular occurrence, but, with hindsight, if acted upon may have saved a lot of trouble.

2.12. In my life I have only ever had one sexual partner – my husband – I have never taken intravenous drugs, I have no tattoos, though I did have my ears pierced at Selfridges many years before I received my transfusion (1975). I have considered that I may have contracted Hepatitis C when undergoing my hysterectomy, but I did not receive any blood at this time and the Skipton Fund accepted my transfusion as the source of infection.

2.13. In June 2016, my GP wrote to an endocrinologist asking advice about my blood tests. He advised that initially I should have all major organs scanned. This took place at an out-sourced private facility whose computer system did not intersect with that at Norfolk and Norwich University Hospital for transmission of images. This was the beginning of the road to my Hepatitis C diagnosis.

2.14. Nothing further happened until November 2016, when I began having blood tests and more scans, of which there were to be many.

2.15. It was at this time that I received a letter from my Consultant Hepatologist at Norwich Liver Service, referred to as (**WITN0024007**) which indicated that I had "a couple of cysts in [my] pelvis", which would be investigated further by another department (see paragraph 5.2). Communications between departments were not good.

2.16. I found out that I had Hepatitis on 12 January 2017, in a letter from my Consultant Hepatologist, referred to as (**WITN0024003**). Upon receiving this letter, I noticed that it was half unsealed. The Consultant had noted, "rather surprisingly they (my test results) have shown you have a chronic viral infection with a hepatitis virus called hepatitis C".

2.17. I was told at a subsequent interview that there was anti-viral treatment available for Hepatitis C, though it was not immediately available. I was further told that there was a waiting list and budget concerns, which meant that certain people would be prioritised over others.

2.18. This was further reiterated in another letter from my Consultant Hepatologist dated 23 February 2017 and referred to as (**WITN0024006**) where I was informed that following a FibroScan, I had "very mild scarring" in my liver, which meant that the Hepatitis had not caused severe damage. Consequently, those with severe scarring would be prioritised over me. Perhaps I have escaped major damage because of the lifestyle I have led.

2.19. I took some issue with this, as I only contracted Hepatitis C because of the action taken by the NHS.

2.20. I was additionally told that a 1-dose treatment had fewer side effects than an alternative treatment. What these side effects were was not shared with me.

2.21. I was asked if I could refrain from drinking for three months, which was fine with me. That was about the sum of the information I received at that time.

2.22. I consider the method in which I was informed of my infection to be entirely inappropriate and maladroit. When someone has a serious illness, they should be told in person. Given that I was not even told I was being tested for Hepatitis C, this is particularly important.

2.23. I think at some point it was thought that I might have a viral infection or a malfunction of the liver. I was subject to a great number of tests, but was not told what specifically they might be for.

2.24. Additionally, I was not asked if I had ever received a transfusion. I did not volunteer this information, as I was unaware that it had posed an infection risk, or was under consideration in my case.

2.25. I have no recollection of being given any guidance to prevent contamination of those around me, and was not warned of any risk of cutting myself near my family. I did, however, know I should notify my practice nurses and my dentist, which I did.

Other Infections

3. I cannot help but think retrospectively about other infections and health issues. Nothing official has ever been said that there might be a link between my ovarian and fallopian tube cancer and Hepatitis infection. However during my own research and that conducted by my husband, there have been some American studies, which suggest that there is a link.

3.1. I am inclined to think that there may be a link between the two, as I overheard some Gynae nurses discussing the fact that I had been signed up for an ovarian cancer research programme, though I had not even been diagnosed with cancer at this point.

Consent

4. I initially gave consent to receive the blood transfusion. However, none of the dangers associated with transfusions were explained to me at the time.

4.1. I have received numerous blood and liver tests since November, 2016 though I have rarely been informed of what I was being tested for. Indeed, I was not told that I was being tested for Hepatitis C, which point I raised with my Consultant in the letter referred to as (**WITN0024004**).

4.2. **GRO-C** **GRO-C** I later gave my consent to be tested for HIV, **GRO-C** **GRO-C** All tests came back negative.

Impact

5. The liver nurses who provided my treatment and support were brilliant. The consultants, however, were not very active. The nurses were responsible for the management, treatment and checking of blood tests. I felt comfortable to ring them at any time, any day and they would be willing to speak to me and answer questions or offer advice.

5.1. I have had a number of other medical complications since receiving my transfusion, though am unsure of how many can be attributed to it.

5.2. I received a diagnosis of cancer following an operation in March 2017, and was offered chemotherapy in May/June 2017, following further surgery for very extensive lymph node removal.

5.3. The two consultants I saw, one for a second opinion, gave differing advice. One said quite clearly that he would not have offered me chemotherapy as I was not fit enough. The issues with my blood would mean that the chemotherapy could possibly kill me if I contracted an opportunistic infection during treatment (both consultants worked in the same team).

5.4. After doing my own research into statistics for five-year outcomes of receiving various chemotherapy treatments for ovarian carcinoma grade 2 versus declining it, I decided that the difference was so marginal, that it would not be in my best interest to undertake chemotherapy at that point. As I had declined the chemotherapy, it was now appropriate for me to return to the liver clinic for my HCV to be treated, as advised by the consultant who gave the second opinion.

5.5. Instead of chemotherapy I had blood tests every 3 then later, 4 months, to check CA125 readings combined with regular internal examinations, which I was and am happy to continue to do. At this time my blood tests all returned within the normal range, as, indeed, they had done when I still had carcinoma. The blood tests are to continue for five years. My oncologist-gynaecologist has been amazing in surgical skills and support during surgery and ever since.

5.6. Lymph nodes are removed as a diagnostic tool and also to forestall metastases. After much discussion I had an extensive procedure to remove mine from the chest area to the groin in a four-hour operation in May, 2017, during which I had to remain up-ended. This posed a risk to my glaucoma and my eye surgeon was consulted and agreed the go-ahead. It transpired that the nodes were totally clear of cancer cells, but I had had a full removal.

5.7. I suffer from increasingly painful osteo-arthritis and joint pain since the anti-viral treatment, though cannot be certain that this is related to the medication. I believe it is.

5.8. I have repeated bleeds under the skin of my fingers and toes. It starts with a slight itch, which when scratched or under pressure feels 'fizzy' and then my finger or toe swells up and goes black. I then get a dark bruise. This can happen from minor contact with surfaces, for example, from turning a door handle to lightly holding the edges of a table.

5.9. Not only is this condition inconvenient, but also causes me pain in my hands and feet.

5.10. I first told my doctor about this approximately 20 years ago. However, whenever I saw a consultant about the issue, I was not experiencing a flare up. I eventually gave up on this investigation and there has been no follow-up since. It has got worse. I reported this to the second opinion oncologist, who said, "What if a bleed happens in your head?"

5.11. These mini-bleeds happen fairly frequently, and increasingly so in my toes. My last flare up was around two weeks before making this statement.

5.12. I have also experienced what looked like extensive red and peeling eczema all over my arms, shoulders and abdomen during anti-viral treatment and eventually got an appointment booked with a consultant to discuss this. However, as this was shortly before the completion of my HCV treatment I did not attend. The referring liver physician I saw at the hospital about this thought that this problem was probably related to the anti-viral medication.

5.13. I have always had low blood pressure but since January 2018, I have been hypertensive. I think this may be stress-related; GRO-C GRO-C. I am still on medication for high blood pressure and expect to be so for the foreseeable future.

5.14. I have suffered with glaucoma since the age of 17, though it was under control until 3-5 years after my transfusion. Of course, this could be coincidental, and it could have in part been due to deterioration and scarring from previous surgeries, but of this I cannot be certain. I have had eye surgery in an attempt to rectify or prevent high ocular pressure and to conserve as much sight as possible. Surgical procedures continued through 1990s – 2016. I am now almost sightless in my left eye.

5.15. When I received my Hepatitis C diagnosis, I was told that I would be put on a waiting list to receive treatment, as the treatment for my cancer was to take priority. I expected to be on this list for a long time, but when following two major cancer surgeries in March and May, 2017, I declined the offered chemotherapy, it was not long before I received a letter from the lead nurse saying that a space had become available and treatment could begin.

5.16. When I was made aware that I would require treatment, I hoped for the single-dose daily treatment, which resulted in fewer side effects (I am unable to recall the name of this), but this was no longer available. Consequently I was put on a course consisting of 5 tablets a day. I asked why I had been put on the 5-a-day treatment, now including Ribavirin, and received the response: "because we can". It was thought to be helpful.

5.17. I understand the need to be pragmatic about cost, and these 5 tablets may be cheaper than the former single dose medication previously available; but unpleasant side effects will inevitably result in patient non-compliance and a large number of those with HCV remaining untreated or even undiagnosed.

5.18. The medication I received was Viekirax (2 per day), Exviera (1 per day) and Ribavirin (2 per day). However, I could not tolerate the Ribavirin, which made me feel very unwell mentally and physically. I did not feel in control, it was like nothing I have ever experienced. The only thing I can relate to it is a bad case of the 'flu – not so much a physical feeling, but very much in my head. It was both depressing and debilitating and I was reluctant to leave the house feeling like it.

5.19. I became very short-tempered, upset, lacking patience and generally felt very overwhelmed. The frustration included not really having time to focus on myself, GRO-C GRO-C

5.20. After consultation with the specialist nurses, I ceased taking Ribavirin after 12 days. Stopping the Ribavirin was not without its effects, but I felt 500% better than I did whilst I was taking it.

5.21. I was in receipt of treatment between October 2017 and January 2018. It is standard practice to remain on treatment for 2 months after the viral load becomes undetectable, which is what I did. I am now clear of HCV and no longer take medication for it, but do have regular blood tests to check its levels in my body.

5.22. My next appointment for a Hepatitis check-up is January 2019, which will be one year since I completed treatment and I will be signed off from receiving specialist care, providing my blood tests remain normal. After that, I will be checked on from time to time, as HCV is known to make recurrent appearances.

5.23. I have already decided that should the Hepatitis come back, I would not take the treatment again. This is in part due to my age, and in part due to the impact it had on my body. I lived untreated for a long time, and am prepared to do that again, should it become necessary.

5.24. I like to manage and take control of my life, but I am finding it harder and harder to do due to issues of fatigue and stress.

5.25. I was aware that I should inform my dentist, which I did. They said it was not an issue and that they would take the same aseptic precautions as they would for any other patient. They treated me the same as they always had, though it remains on my notes that I am a 'danger' and a risk of infection, despite no longer being infectious.

5.26. It is not something I wish to be defined by, though I do understand the need for there to be a warning on my notes.

5.27. I used to be a very proactive and busy woman but since my transfusion have been plagued by fatigue. I began to think it was anaemia or normal for women of my age, but now think that this was unlikely to be the case. This fatigue did not always prevent my going into overdrive with nervous energy, however.

5.28. I suffered no familial repercussions, other than shock. There were no family problems related to ill-informed prejudice. At one point, my stepdaughter from my husband's first marriage came to nurse me.

5.29. I do not recall whether my husband held any strong views about my infection with Hepatitis C immediately after diagnosis, other than shock and disbelief. He was angry for a time and remains incredulous that such a thing could have been allowed to happen and remain undiagnosed for thirty years.

5.30. When I told my children about my infection, my daughter-in-law (who is a senior nurse) told me that I am "not the kind of person I'd expect to have HCV". I think normally there is an assumption that people with Hepatitis C are involved in sex work or drug use – the marginalised of society. I took her comment to mean that I do not fit the stereotype and she was puzzled as to how I might have become infected.

5.31. My children were brought up to be well-informed. Their father was a GP and one of our close family friends, in whose company they spent a lot of time when he was in the UK, was HIV positive. They have not, therefore, treated me any differently upon learning of my illness. Indeed my sons have supported me throughout and attended numerous medical appointments with me to ask questions of my consultants.

5.32. They have been very supportive, despite being initially startled by my diagnosis and shocked by the manner in which I was told. They have all devised ways of managing my illness.

5.33. I entered academia late in my life, beginning university at the age of 50. I might have achieved a career had I started earlier, but many women with young family rule themselves out and it never occurred to me that I might want to pursue such a course then. Fatigue is always an issue when combining such commitments.

5.34. Following my attendance at an evening class in which I completed my English A Level and achieved the highest grade possible then, I was offered a place at the University of East Anglia. It was particularly fatiguing and I could not have attended if my husband had not been willing to pick up the slack at home. I went on to study History at an undergraduate level, before completing my Masters and PhD.

5.35. I was fortunate in that it cost me cost me nothing in fees to attend university, and for higher degrees I received first a bursary for my Master's, and later an award from the British Academy (AHRB) to study for a PhD. I later published this research as a book entitled *Women and Religion in Late Medieval Norfolk*.

5.36. I had to commit to my studies, and be disciplined in my work. It was both tough and very tiring; if I had been overwhelmed by health issues I would have had no choice but to quit.

5.37. For the first time, my husband has had to consider that I may not outlive him (he is 19 years my senior). In January 2017, despite inoculation, I got the 'flu very badly, and he thought I was going to die. I was unable to get from bed to my bedroom door on the top floor of our house, GRO-C GRO-C GRO-C

5.38. As I was so unwell, I did think it important to consider my end-of-life arrangements. As I make this statement, I have just sent off my application to give my sons Lasting Power of Attorney.

Treatment/Care/Support

6. Aside from having to wait for treatment for my Hepatitis, as discussed at paragraph 2.10, I did not face any difficulties in obtaining treatment.

6.1. I arranged to see a counsellor in early 2017 for approximately four sessions. A session lasted 45-50 minutes and cost £40 a session, which I paid myself. I did not continue these sessions as I felt I was deriving no benefit and not moving forward.

6.2. I did discover that I could apply for help with fees, but more form-filling did not appeal to me and the sessions only lasted a matter of weeks. Also, rightly or wrongly, I felt the payments I am receiving are meant in part for such needs.

6.3. The counselling was not particularly helpful, and I spent the majority of sessions in tears. It seemed to me that the recent medical issues I was experiencing - being at a risk of blindness, my recent Hepatitis C and cancer diagnoses, GRO-C and lack of breaks from these - could easily act as a conduit for other historic unresolved and unresolvable issues. I decided that I could weep elsewhere for free.

Financial Assistance

7. I was initially unaware that there were schemes available to provide money to those of us who had received infected blood. I only learned about the Skipton Fund from the liver nurses who had been helping to treat me.

7.1. I applied to the Skipton Fund in July 2017 and was awarded a £20,000 Stage 1 payment in addition to a monthly payment of £252.50 and a winter fuel payment of £505.

7.2. Following the change to NHSBSA for EIBSS in November 2017, my payments were reassessed, upgraded and backdated to 2 October 2017. These were monthly payments of £252.50, a backdated one-off SCM of £4,797.50 and then £1,262.50 monthly.

7.3. From April 2018, my monthly payments increased to £1,500.

7.4. In August 2018, I received an income top-up payment of £362 monthly.

7.5. The application process was fairly long-winded, though I did not find it particularly taxing and did have the benefit of assistance from the liver nurses. I do think some people may have struggled with it, as it was not always clear precisely what the questions were asking.

7.6. There were no preconditions imposed on my application for financial assistance.

7.7. I did, however, receive a letter from the Skipton Fund, which advised me to be careful with whom I shared information about my infection because some people found it a difficult situation, and responses might well be negative and unpleasant. Despite this, I am not too concerned about people knowing, because I have done nothing immoral or negligent to contribute to my being infected.

7.8. I was very surprised to receive anything in the first instance, as I had been given no indication that there was any financial assistance available. I initially thought that compensation schemes might be a way for the government to deflect infected people from seeking redress from the courts.

7.9. I was glad to receive financial assistance as I have no private pension and only half a state pension – I have not worked full-time for a salary since having my children and thus never qualified for a full state pension (I worked in a voluntary capacity for many years). We live a fairly modest life, so I was amazed by the payments, they have been very useful at a difficult time.

Other Issues

8. Prior to receiving my transfusion, I was a blood donor, though I only donated two or three times between 1983 and 1985. I expected receiving a transfusion to be a slightly elongated and reversed process. This was clearly not the case.

8.1. I knew I would be turned away if I tried to give blood after receiving my transfusion, as I had heard public service broadcasts stating that people who had received blood prior to 1992 should not volunteer as donors as a matter of routine precaution. I had heard about issues with contaminated blood in America, but simply did not make any connection between this and my own transfusion.

8.2. Everyone tells you that your life will be different and better after treatment, but that has not been my experience at any juncture of my life. For example, after transfusion, after hysterectomy, after some of my eye surgery, and after treatment with anti-viral drugs.

8.3. I hope I am able to contribute to the inquiry in some small way in order that information around regulation and all medical procedures may be made more widely accessible in the future and that sound medical decisions may be made for reasons not driven by budgets or self-protection.

Statement of Truth

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

Signed GRO-C

Dated 19th October 2018