Witness Name: Anna Franklin
Statement No.: WITN0228001
Exhibits: WITN0228002
Dated: 15th May 2019

# INFECTED BLOOD INQUIRY

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# WRITTEN STATEMENT OF ANNA FRANKLIN

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 07 November 2018.

I, Anna Franklin, will say as follows: -

## Section 1. Introduction

1. My name is Anna Franklin (maiden name Anna Murphy). My date of birth is GRO-C 1967. My address is known to the Inquiry. I am a single mother of two children and I work part-time at the University of Bath.

2. I intend to speak about my infection with Hepatitis C and the impact it has had on my life. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment received and the long-term effects on my life.

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

## Section 2. How Infected

4. I was infected with Hepatitis C in 1986 at St Mary's Hospital Manchester, during an amnion tissue graft to create a vaginal canal. I needed this surgery because I was born with a condition called Mayer-Rokitansky-Küster-Hauser syndrome ("MRKH"), which meant that I had ovaries, but no vagina and cervix, and only a partly formed tiny uterus.

5. My parents and I first realised that something might not be right when I reached my mid-teens without starting my periods. When I reached 16 and still hadn't started menstruating, my mother took me to see our GP Dr Clarke who, after an examination, referred me to St Mary's Hospital in Manchester for a laparoscopy. This showed that I had no uterus, cervix or vaginal canal.

6. At that time, I wasn't given a name for my condition, but I was told that I would never be able to carry a child. This news was delivered very bluntly and without any empathy. I was also told that without further surgery to create a vaginal canal, I would never be able to have a full sexual relationship with a partner. It is very hard to put into words how traumatic and incredibly distressing this was for both me and my parents. We were in complete shock.

7. My mother then came with me for support to the post-surgery follow up appointment at St Mary's with Dr Warrell. We were informed of the two available surgical options at the time to construct a vaginal canal: I could undergo a new procedure to use tissue from a donor placenta to form a skin graft, which would be used to line my vagina, or I could use a skin graft from my thigh to do the same, but this would leave me with another fairly large scar. The latter had both medical and aesthetic implications, so the obvious and less risky choice seemed to be the donor placenta tissue option, which was made to sound much more preferable in terms of recovery and scarring. I think Dr Warrell was also keen to try out this relatively new surgical technique, so steered me in this direction.

8. It was August 1986 and I was 18 when I had the surgery. I was in hospital for almost three weeks and had three operations. They seemed to go well at the time and I recovered over the following few months.

9. In the late eighties and nineties after the surgery, I definitely struggled with ongoing fatigue and a depleted immune system, but at the time I just put it down to bad luck and nothing more. I now realise quite a few issues were symptomatic for Hepatitis C.

10. I met my now ex-husband in 1998. For the first few years we were together, having a family was not something we were focussed on but by 2002-2003, I became very conscious of my age as I was in my mid-thirties by then. I felt like I was running out of time to start the IVF treatment needed to have a child via surrogacy. In 2003, my ex-husband decided he was also ready to have children, so we contacted a surrogacy agency to help us start the process.

11. It was only when the representative from the surrogacy agency came to see us that I first heard there was a medical name for my condition. I learned that it was called Mayer-Rokitansky-Küster-Hauser syndrome, and the representative reassured me that I was not unique in having been born with it. We were told to expect a long wait to be matched with a surrogate, so we could not believe our luck when a few months later we were notified that there was a surrogate who was keen to meet us. This was in the autumn of 2003 when I was almost 36. In early 2004, we were able to go to a fertility clinic in Southampton to start the process for surrogacy, part of which were the standard preliminary blood tests.

12. I remember the day that I received the results of my blood test so vividly. It was a beautiful day outside. I felt really happy and hopeful about the journey ahead to have a much-wanted family, and we had many exciting plans for our future. The letter that came in the post from the fertility clinic literally shattered my world. I could not believe what I was reading and everything suddenly seemed very surreal. The letter was brief; it simply

stated that they would not be able to help us any longer with the surrogacy as I had tested positive for Hepatitis C.

13. I was distraught, confused and panicked upon reading this news. It was literally devastating: the only thing that had barely prevented me from having a breakdown after my diagnosis of MRKH almost 20 years earlier was the thought that I would be able to be a mother one day via surrogacy. Now, I was being told that surrogacy was not going to be a possible option because of the Hepatitis C, not just in Southampton, but at any fertility clinic. The diagnosis took all my hope away.

14. I spoke to the clinic on the phone but they were very insensitive and unhelpful. In addition to stating again that as a matter policy, they would not treat me as I had Hepatitis C antibodies present in my blood, the nurse said I must have caught it via something I had done.

15. They offered no other help and they just said that I should speak to my GP. There was no explanation about the possibility that I might only have the antibodies; in their opinion, I had Hepatitis C and that was it. I did not even know what Hepatitis C was; it was not explained to me in the letter and the only information I could find was on the internet, which sent me into a panic as the prognosis seemed so awful. From the information online, the realisation quickly came that this was not just an issue in relation to the surrogacy, but that it might also have a huge, potentially life-limiting impact on my health. Both my ex-husband and I were very, very scared.

16. In addition to their dismissive manner to me, I was also informed that the fertility clinic had called my surrogate and told her that I had Hepatitis C. The clinic told her this information without my prior knowledge or consent, which was a breach of my right to patient confidentiality. I was not hiding it from her, but at that stage, I did not even understand the situation or implications myself, so I did not want to inform my surrogate of my condition until I could properly answer her questions. There was no risk to

her and I felt I needed to fully understand the situation before I spoke to her.

17. Following the clinic's response, I went to see my local GP in Hampshire, near where we were living at the time. The GP turned out to be blunt, uninformed and overall monumentally unhelpful to me. I had a very routine ten-minute appointment and was made to feel like a real inconvenience and a burden. The doctor implied that I must have done something to catch Hepatitis C, that it was somehow my fault and that he should not have to do anything to rectify a supposed mistake of mine. However, I persisted and insisted that I was referred for further investigations: I needed to know if I had just the antibodies or the full-blown virus, firstly with regards to my health and secondly to be able to tell our surrogate.

18. The GP eventually agree to refer me to a liver specialist at Basingstoke Hospital, but told me to expect a wait of about three months to be seen. This was a big concern, as I was terrified about the damage the virus might be doing and had already done to my liver. I also felt a huge sense of responsibility towards our surrogate and needed to let her know what was happening. By this stage, we had become very good friends. She was incredibly supportive and was still keen to help us if she could.

19. Our lives completely stopped at this point. Sometime later, while I was still waiting for a letter with an appointment date to be seen in Basingstoke Hospital and I was at home feeling distraught, a programme about the liver unit at King's College Hospital came on the television. I rang them and they gave me a name for the consultant that I should contact about an appointment. This was Dr Phillip Harrison.

20. I also called St Mary's Hospital, Paddington and a few other hospitals in London, but I was informed by St Mary's that it was taking six to twelve months for the consultant to see anyone through the NHS.

21. My then husband and I decided to go and see Dr Harrison from King's privately, something we could ill afford but we were so desperate for

answers and we were finding it extremely difficult and stressful just waiting at home and not understanding what it all meant. The major priority at that stage was to find out if I had the virus or just the antibodies, as we had been told that fifteen percent of people who contract Hepatitis C could apparently clear it naturally. There was also the massive worry of whether I had passed the infection on to my husband.

22. We went to see Dr Harrison at his private practice at London Bridge. He did the test GRO-C ; he was straight talking but kind in explaining the possible implications of the results. We had to wait about a week for the results, and when he called us, we were told GRO-C have the disease, but I did. By this stage, we were relieved to have a clearer understanding but were obviously emotionally and mentally exhausted by the trauma of it all.

23. Dr Harrison informed me that if I got a referral letter from my GP, he would be able to treat me under the NHS at King's College Hospital, where they would perform a liver biopsy to determine how badly the virus had damaged my liver. This was done around the end of May or beginning of June in 2004. Thankfully, compared to what I had been told when I called other hospitals, this was a relatively short timescale. I think Dr Harrison was considerate of the fact that our fertility treatment was on hold, and due to my age, time was a serious issue. The fertility treatment, which we were so desperate to have, could not proceed if I could not be treated for the Hepatitis C.

24. Everyone in the medical profession that I had contact with prior to seeing Dr Harrison at King's were consistently of the opinion that I must have contracted Hepatitis C via drug use, despite me saying every time again and again that I had never used drugs. Their manner towards me when I said I had never used drugs was as if they thought I was lying. There was never any comfort or reassurance.

25. Dr Harrison was the first to ask me whether I had ever received a blood transfusion. I was about to say no, but then I remembered and told him

about the placental tissue transplant at eighteen. I do remember that a few years after the transplant, with all the stories in the media, the thought did cross my mind that maybe there was a possibility that I could have contracted HIV from it. However, this thought was so scary that I was too frightened to be tested and I tried not to dwell on it.

26. As I have explained above, prior to undergoing surgery at 18 I was given the option to either have a transplant of tissue from my thigh to form a vaginal canal, or to have a transplant of placenta tissue from a donor taken at the time of them giving birth. I was informed that the benefits of the latter were twofold. Firstly, I would not have a scar on my thigh and also not have an additional surgical site and the associated risks. Secondly, amnion tissue is softer and easier to mould. It also has a high level of blood stem cells, which meant rejection was unlikely.

27. I remember my mother asking who would donate a placenta. Dr Warrell responded that they had many prostitutes giving birth at the hospital, so sourcing a placenta from one of them should not be a problem. I informed Dr Harrison of all of this, and he agreed that the most likely cause of transmission of Hepatitis C to me was through an infected placental tissue graft. I exhibit a letter from Dr Harrison to Dr Hayward dated 20 July 2004 as WITN0228002 as confirmation of the above.

28. The fact that initially they couldn't understand how I had contracted Hepatitis C was incredibly painful and confusing. It added massively to the horrendous levels of sadness and distress. I felt like I was existing rather than living, just getting from day to day waiting for each test or doctor's appointment. Any semblance of a normal life had disappeared the minute that letter arrived; it is impossible to articulate the emotional impact, the trauma of that time and the overwhelming sense of hopelessness.

## **Section 3. Other Infections**

29. When the blood tests were done by the IVF Clinic in Southampton I also tested positive for CMV (Cytomegalovirus).

## Section 4. Consent

30. When I received the placental tissue graft during the surgery I had at eighteen to create a vagina, I was treated without being given adequate or full information. Nothing was ever said to my mother or me about the risks of contracting any type of virus from the transplant. Initially, I had no worries or concerns. Then in the nineties I only worried about AIDS, not because of any information regarding risks of viral transmission from the doctors or medical staff but because of the level of media coverage at the time. I never heard anything about Hepatitis C.

31. There was absolutely no way that either my parents or I would have agreed to the amnion tissue transplant if the risks had been communicated to us. I would have chosen to have a skin graft from my thigh instead, where there was no possible risk of infection transmission.

## Section 5. Impact

32. It is almost impossible to quantify or articulate how being infected with Hepatitis C has affected me on every level, emotionally, physically and mentally. The overall impact on every area of my life has been immeasurable. I have suffered not just from the impact of the illness and its symptoms, but also the impact of the treatment, the ongoing impact of the side effects, the impact on my ability to work, the impact on my marriage, the impact on my ability to have children through surrogacy and the impact on me as a person. I am not the same person I was before I received that letter from the fertility clinic; the scars are lifelong.

33. Following my liver biopsy in mid-2004, the only option for me to have any chance of being able to go through IVF was to undergo a course of treatment to try to clear the Hepatitis C virus. The treatment was a course of Pegylated Interferon and Ribavirin.

34. The damage to my liver was a level below the criteria for automatic treatment, but due my urgent fertility issues Dr Harrison was able to authorise it, as he was in charge of Hepatitis C treatment for the South East of England at that time. The timing was fortunate for me: I remember Dr Harrison informing me of a policy change coming into effect from the end of 2004, which would have precluded him from authorising my treatment. If I had gone to Dr Harrison the following year, I would not have been able to have treatment. This would have resulted in further delays to IVF treatment or no IVF treatment at all, and I dread to think what might have happened in terms of further liver damage.

35. Prior to receiving the treatment, Dr Harrison did explain the risks and side effects that might occur whilst I was taking it but that they would only be for the duration of the treatment. They were daunting, but as this was my only possible option with regard to any future surrogacy, I felt that I had no choice but to undergo the treatment. Whilst I still tested positive for Hepatitis C, no fertility clinic would even meet to discuss treatment with me, let alone actually treat me.

36. The only slight positive news that I had at that time was that I had genotype 2b of the disease, which meant that I only needed a six-month course of treatment rather than twelve months. I started treatment in September 2004 and learned to inject myself with Interferon into my stomach. I had to do this every week, in addition to taking the Ribavirin tablets.

37. The side effects of the Pegylated Interferon and Ribavirin were awful; it felt similar to chemotherapy (I have subsequently been treated for breast cancer with chemotherapy and therefore I am well placed to draw the comparison). I suffered terrible migraine headaches and generally felt very unwell. I suffered from nausea and felt utterly fatigued. I had very flu-like symptoms, and my mood was very low because I did not have any energy to do anything much at all. My hair did not fall out but it did thin dramatically.

38. Before I started the treatment, I had a marketing contract job at a large bank in London, and I was commuting every day from Hampshire. However, when I started the treatment, there was no way that I could continue with the work and commute. I was simply too ill. This severely impacted on our household finances (my ex-husband, then fiancé was in the early stages of setting up a business) and caused a huge amount of added stress and worry to an already very difficult situation.

39. It was an immensely challenging period for us for a number of reasons. I had been made redundant around the time of my diagnosis with Hepatitis C, and we were trying to move to GRO- as it provided a better business opportunity for my fiancé. GRO-C GRO-C GRO-C GRO-C GRO-C Even with this increased pressure from the mortgage, I still had to give up my contract job because I simply could not do it with the side effects of the treatment.

40. In the end, we made the decision to move regardless of the house sale as things were just so awful and we felt stuck in such a depressing situation. It was such a terrible time, because people just did not understand what it was like to live with hepatitis, let alone undergo the treatment with all the associated side effects. I only told my close friends and family that I had Hepatitis C, but they did not understand how serious it was.

41. The other reason why I did not tell people about HCV is that I had barely told anyone about my surgery at all – it was so personal. If I told people that I had Hepatitis C, they would always ask how I got it and I could not bear to have to explain the surgery and the graft. I felt extremely isolated, trapped at home without seeing anyone.

42. I had to declare my infected status on medical forms and cope with people asking how I had contracted Hepatitis C. The way people asked always implied that they assumed I had been infected through taking intravenous

drugs, or via some other self-inflicted route. I used to tell them it was from a transfusion so that I did not have to explain about the graft, which I felt so horrified about. With hindsight, it was a stark contrast to having cancer, because then people could relate and be hugely sympathetic and supportive towards me.

43. I was so completely alienated at this time, that even my best friend did not visit me. I later asked her why she did not come the entire time that I was unwell, to which she responded that I was not a very nice person to be around. In truth, this was probably accurate as I was so angry, confused and just felt such an overwhelming sense of hopelessness that it was impossible to enjoy any aspect of life.

44. I resented my friends for being able to have fun, to do normal activities such as go on holidays, have social catch-ups, get married and start families, when all I was able to do was sit at home feeling permanently ill with my life on hold or commuting up to hospital appointments. I was so sad and unhappy that my fiancé and I could not do any of those things that our friends were doing. My life was very dark at this time. I felt sad, robbed of a normal life and guilty at what I was putting my fiancé through. Our relationship understandably struggled with the pressure.

45. I finished my treatment at the end of February 2005 and started a marketing job near Bath two weeks later. I could not give myself the time I needed to recover from the treatment, GRO-C GRO-C GRO-C Almost immediately after starting the job, because my immune system was so weak, I contracted mumps. It was a nightmare to deal with and I was very ill, but I kept going into work because I was scared that I would lose my job. GRO-C GRO-C GRO-C

46. I totally lost all of my self-confidence. I also suffered from depression, had terrible anxiety (including panic attacks), and I suddenly had a bad

memory when I never had memory problems before treatment. All of this made work very stressful and difficult. I completely changed and became somebody that was not me anymore. However, I was so petrified that any of these things would make me ineligible for surrogacy that I held it all within myself.

47. I was very scared, because by 2005 I was 37 years old and time was really ticking with regards to fertility treatment. I would put a smile on my face and say I was fine, even though I was falling apart inside. A scan showed that my ovaries appeared to be normal and functioning, but I could not know for certain until I'd completed the IVF treatment. It was a huge amount for me to deal with emotionally and mentally.

48. I had one blood test in February 2005, the week after treatment finished, and another six months later, which showed that the virus was undetectable. The Hepatitis C antibodies, however, remain present in your blood. This was an ongoing issue with regards to the fertility treatment, the tests they do and their criteria for treatment. I was advised to wait for another year before starting IVF treatment, because Ribavirin can cause birth defects. We therefore had to wait until 2006 before starting IVF treatment, knowing that I would be at least 38 when the treatment started. This caused more stress, as our chances of success decreased massively the nearer I was to 40.

49. In the meantime, I spent the year ringing all of the fertility clinics to try to find a clinic that would treat me. Despite going through treatment and clearing the virus, I still tested positive for the antibodies. Because of this, all of the fertility clinics still refused me, which was really distressing.

50. However, I was desperate and refused to give up. I eventually found a specialist clinic in London (The Bridge Centre) that had experience of washing sperm from AIDS carriers. They were the only clinic even prepared to give me an appointment to discuss the situation. They agreed to treat me, although they had never washed eggs before. The drawback

was the cost; the clinic was twice as expensive as everywhere else was. However, we had no other options so I had to be treated there.

51. The single good thing during this whole period was that my original surrogate had continued to support me and was still willing to help me. For reasons I will never understand but will always be incredibly grateful for, she committed to waiting until I had received the necessary treatment to clear the virus. It was probably the only thing that kept me going. The costs of the treatments were crippling, especially as we were already in such a financially difficult place, but we went ahead as I was so desperate to be a mother. My emotional and mental state could not have coped with us not going ahead.

52. The first embryo transfer with two embryos did not work, but the clinic froze some of the remaining embryos – two that looked perfect and three that did not look so good. Despite their advice, I made the choice to keep the three embryos that were considered 'poor'. We had the next embryo transfer two months later with the two higher grade embryos, but this did not work either. By that point, I was beaten down so far. Life was just about functioning, not living.

53. Whilst this treatment was happening in London, I was trying to move it to the IVF clinic in Bath because the time and cost of travelling to London were draining, with me in Bath and our surrogate in Gloucester. The fertility clinic in Bath had previously turned me down due to the hepatitis, but I was desperate. I tried one more time to make an appointment, but this time I did not tell them about the Hepatitis C at the beginning.

54. When we met with the IVF consultant, he told me that if he had known about my Hepatitis C beforehand, he would have refused to see me. However, because I had then explained that I did not have the virus but merely the antibodies, he would speak to a haematologist and let me know. He then came back to me a few days later and said that they would treat me despite the antibodies.

55. Moving the fertility treatment was time consuming, so before it started in Bath we had one last try in London. We only had the 'poor' embryos left and of those three, two died as soon as they were taken out of the freezer. The final one was on the verge of doing the same and we were almost at the point where the clinic would have refused to do the transfer. However, despite losing half of its cells, it miraculously started to divide again. The clinic later told me that if the last egg had lost one more cell, they would have discarded it.

56. The transfer went ahead and we finally got our miracle. My son is now eleven. He is one of the two reasons why I have persevered thus far to be able to tell my story today.

57. Finally becoming a mother was a wonderful, amazing experience and I think I believed that in doing so, it would suddenly make everything better and take the pain and trauma away. But the reality was that dealing with a new-born baby, whilst managing persistent fatigue and an ongoing low mood from treatment, was difficult and isolating.

58. In September 2006, around the same time our surrogate confirmed she was pregnant, I noticed a pain in my armpit and I was referred to the Breast Cancer Clinic for checks. The doctor told me it was cysts, and that I did not need to worry.

59. When I had had my appointment at the Bath IVF Clinic, the consultant told me that I should have been eligible for IVF funding and said he would make an application on our behalf. Even though our surrogate was pregnant, we decided to continue with this as we hoped in the future for a sibling. I was almost 39, so time was a massive factor and my eggs were deteriorating. However, the IVF consultant told the Primary Care Trust that my son was on the way, so they took back my funding and said I could not have the financial help. I decided to appeal their decision as certain aspects were so contradictory, and was successful with the appeal.

60. As a result of getting this funding, I went through another round of IVF treatment in May 2007 and the embryos created were frozen. A year after my son was born, my surrogate said that she would help me again to have another child. Therefore, in 2008 using the embryos created the year before, we went through the process again. The second transfer was successful, and resulted in our beautiful daughter who is now nine years old.

61. In February 2011 when the children were three and one year old respectively, I realised one morning that one of my breasts looked odd. I instantly felt panicked. I went to the GP who referred me straight back to the Breast Clinic. In the same breast where I had previously been told I had cysts, I now had a huge cancerous tumour and cancerous lymph nodes in my armpit that had been growing for years. I was distraught and terrified.

62. The news was truly soul destroying. With two small children whom I had fought so hard to have, and a marriage that was already at breaking point as a result of the Hepatitis C, I really did not know how I was going to get through it.

63. I underwent chemotherapy and radiotherapy treatment at the Royal United Hospital in Bath from April 2011 to December 2011, with a brief break in August when I had a radical mastectomy. The chemotherapy was brutal on every level, and the side effects were life limiting. With us still struggling financially from the impact of Hepatitis C and absolutely no savings, my husband was only able to provide limited day-to-day support with the children, as he had to bring in an income.

64. Thankfully, I managed to clear and survive the cancer as well but with the physical and mental effects of the Hepatitis C treatment and then the treatment for cancer I was totally broken. One thing of note though, was that the support that I received from friends and the medical profession for cancer was unlike anything I had ever received for Hepatitis C.

65. Unfortunately, my medical complications did not stop there. After the tumour in my breast had been removed, I had to wait a year for reconstruction surgery. The hospital offered me a few options; it was difficult to know how to move forward as the recovery was going to be difficult with the children still so young. I chose the option that seemed to offer the best chance of a quick recovery, but it was riskier for someone who had undergone radiotherapy. It was also a sad attempt to try to save my marriage.

66. The initial implant surgery went well, but when the doctors tried to expand the implant, it was unbelievably, horrifically painful. A month before I was scheduled to have surgery to have the tissue expander removed and a permanent implant inserted, my chest split open. It turned out that my skin and muscle were too damaged and could not cope with the pressure. I had to have emergency surgery, and then wait a year before I could try another type of reconstruction. At this point, my husband told me he wanted to leave.

67. I am one hundred percent certain that I would not have developed breast cancer at 43 had I not been infected with Hepatitis C; there is no history of breast cancer in my family. In my view, it was the huge trauma of the hepatitis treatment, the emotional and psychological impact of the diagnosis, and the huge difficulties and barriers it created for my chances of becoming a mother through surrogacy that caused my cancer. It was a "perfect storm" physically, mentally and emotionally and created a state in my body where the cancer was able to grow and take hold.

68. At the Breast Unit, the specialist nurses said that there was a pattern of women developing breast cancer after a severe traumatic life-changing experience, especially where the person had suffered in silence. With the Hepatitis C, not only was I not able to talk to anyone who truly understood, but I also felt embarrassed and devastated by the fact that I had contracted it through such an incredibly personal gynaecological procedure. I have since found some medical research where the

conclusion is that people who have or had the HCV virus have a higher risk of contracting a range of different cancers, not just liver cancer.

69. The effects of the Hepatitis C diagnosis still impact on my daily life and is something I have sadly had to accept always will. Emotionally and mentally, I struggle with the constant worry that the cancer will return. With my liver already damaged and vulnerable, I fear that this is where the cancer would take hold and be fatal. I have never had any follow up to the treatment in 2004, so I am not certain how badly my liver is still damaged.

70. The successful career in marketing that I had built up prior to the Hepatitis C disintegrated due to my mental health issues and I have only been able to cope with relatively low level, low paid administrative jobs since.

71. With regards to my marriage, I do not know whether it would have succeeded if I had not contracted Hepatitis C. Regardless, the relentless stress of my diagnosis, treatment and the long-term side effects that meant I changed so irrevocably were huge contributory factors in the breakdown of my marriage.

72. GRO-D GRO-D GRO-D I lived in a state of heightened anxiety and became someone who catastrophised every situation. With no support and the air of secrecy to maintain, the infection was hard for him to deal with GRO-C, and the burden of constantly needing to support me financially and emotionally proved too much. Clearly, marriages fail and it is hard to know how my marriage would have turned out long term, but there is no doubt that it would have had a much better chance without the devastation caused by the Hepatitis C.

73. Hepatitis C has honestly affected my whole family; my mother was heartbroken for me and extremely worried. My children have suffered from having a mother constantly battling fatigue, depression and other long-term side effects, which has inevitably affected our quality of life. My son

is very scared of dying, as he has an increased awareness of it relative to other children due to my health battles. GRO-C GRO-C

74. I have gone from being a highly independent person who travelled all over the world, to someone who after treatment stood in the middle of London having a panic attack, despite living there in my twenties. Not understanding why I did not feel fine and why I felt so depressed only added ten-fold to it. I was told I would feel OK when the treatment finished, but I did not. The trauma carried on and on, and I suffered so badly in silence, not knowing what to do. There are too many times to count when I have just sat and cried my heart out, unable to cope with life.

## Section 6. Treatment/Care/Support

75. The mental health challenges are ongoing, but in the last few years I have learned some mechanisms which help me cope better with all the trauma and its aftermath. However, this has only come about from the cancer and not because I was offered any counselling or therapy due to having Hepatitis C.

76. At the time of my diagnosis and treatment for Hepatitis C, my mental health was referred to only very briefly. This was in the form of a basic tick-box questionnaire, and I was petrified that if I answered negatively it would affect my chances of receiving fertility treatment. For this reason, I put on a 'brave face' and pretended to be fine whilst inside I was totally empty.

77. I was definitely not informed of any long-term issues regarding anxiety, depression or anger, and these proved severely debilitating in the months and years afterwards. The side effects that were discussed with me focused only on physical effects, such as achiness or headaches. The mental and psychological effects were overlooked, as the general

consensus at the time was that the side effects would last only as long as the treatment.

78. The lack of support offered for Hepatitis C stands in complete contrast to the wealth of support that was made available to me when I was diagnosed with cancer. For example, to this day the nurses at the cancer unit in Bath Hospital are always at the other end of the phone whenever I am concerned about anything. I have no one to call, nor have I ever had, when I am concerned about any ongoing effects of Hepatitis C. I have encountered two completely different mind-sets within the medical establishment for two equally threatening, traumatic and debilitating diseases.

## Section 7. Financial Assistance

79. I receive financial assistance from the Skipton Fund.

80. Mr Harrison at King's College Hospital was the person who told me about the Skipton Fund being set up. Therefore, I obtained a copy of the application form and went to see my GP in Bath in October 2005, as it required her to sign the form for me.

81. My GP in Bath (Dr Stagg) initially refused to sign the application form. She was extremely dismissive, and was of the opinion that as I must have contracted Hepatitis C through some fault of my own, the NHS should not have to pay for it. She was very rude and blunt, and reduced me to tears with her manner. There was no sympathy or empathy, and the GP left me with the strong impression that I was cheeky to go and ask her to sign this application form for financial assistance. For someone in such a fragile state it was appalling.

82. However, as well as being upset, I was also infuriated by her attitude. I repeated what Dr Harrison had told me: that the most likely cause of transmission was the amnion graft that I had received at 18, and showed

her the letter from him. He had already completed a section of the form for me supporting my application. Dr Stagg was so rude to me, but I stood my ground and eventually she reluctantly signed the form when I stated that I was the victim in this situation.

83. The whole experience with her was horrible and left such a mark that I always opt to see one of the other doctors at the same practice when I need an appointment.

84. I received a Stage 1 payment from Skipton for a sum of £20,000 in the spring or summer of 2006. This barely covered the debts we had incurred as a result of me being unable to work for most of the year since being diagnosed.

85. Thereafter, I did not receive any further payments until I suddenly received a letter in April or May 2017 saying that the NHS Business Services Authority had agreed to pay around £3000 per year in monthly instalments for Stage 1 recipients. They also announced that they planned to introduce a Special Category Mechanism for getting a higher payment. I seemed to meet the criteria, so when they made this available, I completed the application form and had my application granted in March 2018.

86. I now receive £1500 per month from the Special Category Mechanism payment and a further £414 as income top-up, as I have two young children. As a result, I have recently been able to reduce my working hours to help me cope with the ongoing fatigue and other long-term side effects.

## Section 8. Other Issues

87. I appreciate that I am one of the 'lucky' ones to have survived both Hepatitis C and cancer, but in doing so my quality of life has been completely decimated.

88. I should not have had to fight and constantly struggle the way that I had to physically, mentally and financially. It is too much for anybody to cope with. I have worked very hard not to be bitter and angry about what happened to me, and the years lost to illness, hospitals and treatment. My life was turned upside down overnight when I opened that letter in 2004 as a result of something that should never have been allowed to happen.

89. I am simply exhausted emotionally and physically from all that has happened since 2004. When I am feeling very low and struggling to cope with how much my life has been destroyed, my counsellor tells me she has never met anyone who has been through the level of things I have had to endure and still manage to keep going. It definitely is not easy, but my children motivate me to try every day. We all deserve a good quality of life, a happy life.

90. I am grateful for the Inquiry. It is time for there to be an understanding and accountability for what has happened in relation to the contaminated blood and blood products. People were not honest and made terrible decisions, for which so many have suffered and are still suffering terribly.

**Statement of Truth**

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

Signed GRO-C

Dated 15th May 2019.