

Witness Name: Jacky Barber

Statement No.: WITN0715001

Exhibits: **WITN0715002 - 004**

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF JACKY BARBER**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 March 2019.

I, Jacky Barber, will say as follows: -

#### **Section 1. Introduction**

1. My name is Jacky Barber. My date of birth is GRO-C 1962 and my address is known to the Inquiry. I am married with three daughters and I am also a grandmother. I formerly worked as a chef making specialist cakes and later set up a stationery and print business with my husband.
2. I intend to speak about my infection with the hepatitis C virus, which I contracted as a result of being given a transfusion of contaminated blood in 1990.
3. In particular I intend to discuss the nature of my illness, how the illness affected me, the treatment I received and the impact it had on me, my family, and our lives together.
4. I confirm I have chosen not to be legally represented and I am happy for the Inquiry team to assist me with my statement.

## **Section 2. How Infected**

### *How I was infected with hepatitis C*

5. In 1989, I was pregnant with my youngest daughter. At the same time, I was diagnosed with colitis. One serious complication of the colitis was that I was losing a lot of blood and became anaemic. Towards the end of the pregnancy I was on steroids and iron injections because my iron levels had become so low.
6. After the birth of my daughter in the beginning of 1990, my condition worsened and I became extremely unwell. I was not being correctly diagnosed and I was losing weight, passing a lot of blood and my iron levels were dropping. I was transferred to various hospitals including Broomfield General Hospital, Black Notley Hospital and Colchester General Hospital. One consultant, Dr Swallow from Broomfield General Hospital, told me my colitis would not cause my health issues and that they were due to anorexia and psychological problems. However, by 1991 I was properly diagnosed with Crohn's disease and told I did not actually have colitis. This helped understand the symptoms I was experiencing and receive more appropriate treatment.
7. I had been in several hospitals for about nine months and I was not getting any better. I was put on trials for lots of different medications and I was placed on parenteral feeding. Anything I ate caused bleeding in my stomach. I had an allergic reaction and had to stop taking iron injections. Dr Cowan, the doctor at Colchester General Hospital withdrew all iron products, but my iron levels continued to drop and I was passing a litre of blood at a time.
8. I was told I would require major abdominal surgery, but at the same time my body was slowly shutting down and my weight had dropped to around five and a half stone. I had to be physically prepared for the surgery and was told a blood transfusion was required.

9. I was scheduled to have major abdominal surgery on 21 September 1990. In order to prepare me for the surgery, I was supposed to receive six units of blood prior to the surgery. I was unable to receive it all because I was so ill and my blood vessels kept breaking down and I had to keep moving the Venflon. It took about two days to receive the transfusion. I ended up only receiving four to five units because I was too ill to receive the full amount. My temperature was spiking and the remaining blood had been out of the fridge for too long so had to be thrown out.
10. HIV and infected blood was quite a topical conversation at the time that I received the transfusion and my husband and I did have concerns. My impression from everything I read and heard through media coverage over the years was that since the 1970's and 1980's, a transfusion was safe. I remember being concerned about it and wanting to have these conversations with the medical team. When I was first told that I needed the blood transfusion, the surgeon, Dr **GRO-D** assured me that the blood was safe. On the day of receiving the blood transfusion, I had an in depth conversation with the surgical registrar and was reassured by him that I was lucky to have the blood as it was now safe. I recall the registrar saying that if it was a couple of years earlier, they would not have been giving me the blood as it would not have been safe. Both those statements made me feel like the blood was safe and that I did not need to get tested for HIV or hepatitis.
11. About three weeks later on 21 September 1990, I had major abdominal surgery on my bowel at Colchester General Hospital. It was a very long operation in which my large bowel was removed. I lost a lot of blood during the surgery so I was given a blood transfusion for the second time. I am unsure how much blood I received, but I know it was a lot of blood as after the operation Dr **GRO-D** told me they had to send out for more during the surgery. I believe my infection with hepatitis C virus can be pinpointed to this transfusion because I remember having flu and pneumonia-like symptoms for approximately seven weeks after receiving this transfusion. I was discharged from hospital about a month after the surgery.

12. After my discharge, I developed a blood clot in my lung and pneumonia. I was rushed back to the hospital. I remained in hospital for another month. I had fevers and high temperatures, I felt very fluey and unwell. In retrospect, I now believe it is likely this was the hepatitis C infection taking hold.
13. In or around 11 April 1991, I had emergency surgery for a perforated bowel at Colchester General Hospital. During the surgery one of my ovaries became entangled in my bowel and I had my third blood transfusion. I received approximately six units of blood. I do not recall feeling physically unwell after this surgery the same way I had after my major abdominal procedure, but I do remember having severe joint pains.
14. After April 1991, I received further blood transfusions, but by this point they were deemed to be much safer.

*Ongoing health problems*

15. I have had consistent health problems for thirty years which can be attributed to the hepatitis C virus, Crohn's and celiac disease. I have had celiac disease for the past fifteen years. In 1993 I was also diagnosed with rheumatoid arthritis. This diagnosis also led to further operations. On many occasions when I have been in hospital, I have not felt like I have had much support from the doctors and specialists.
16. I recently requested and received my medical notes from Broomfield Hospital. There is an undated medical note from the records I received from Broomfield Hospital signed by Dr O'Donnell who saw me at some point between 1994 to 1995. I had a rash that he thought was due to my sunbathing, but this was not the case. It required treatment with steroids. GRO-D These notes are exhibited as **WITN0715002**. In addition I have another file note dated 24 and 25 March 1993 which discusses the rash and its possible connection to the blood transfusion I received (exhibit **WITN0715003**). My medical records were often not dated or sent in any order. I found this frustrating when trying to piece together what happened.

17. I believe the symptoms of Crohn's I have experienced have been more severe than how most people experience them because of the hepatitis C infection. I have received a copy of one of my medical notes where the doctor records that the pain I was experiencing was not typical of Crohn's pain (exhibit **WITN0715004**). Due to the fact that the hepatitis C went unnoticed for so long, it allowed the Crohn's to go untreated longer than it should have been. The impact on my everyday life may not have been as severe had this infection not occurred or been picked up from the beginning. I have had pneumonia at least five times. For twelve years I was consistently in and out of hospital, sometimes for as long as three months at a time. The past four and half years I have been able to have treatment at home which requires me having a drip in the evening five to six times during the week. Even though I can have the treatment at home, the frequency means it is very disruptive to my life.

*My diagnosis with hepatitis C*

18. It was a fluke that I found out I had been infected with the hepatitis C virus. My rheumatoid arthritis was getting worse and had caused my hand to become deformed. In March 2018, I had a number of blood tests at University College London Hospital (UCLH) after seeing Dr Leandro. Dr Leandro advised me the tests were needed before starting me on a particular trial treatment of a medication called Leflunomide, for my rheumatoid arthritis. Dr Leandro sent me from her appointment to a rheumatologist nurse to get the blood tests. I was not advised what type of blood tests I was having, and I certainly was not informed the tests included the hepatitis C virus test.

19. A few days later I received a phone call from the rheumatologist nurse who told me I required a second round of tests. Since I already had another appointment, she suggested I pick up the blood test forms and have those tests on the same day. I had not even read the test forms prior to having the tests because of the rush before my other appointment and I did not know what I had specifically been tested for.

20. On **GRO-C** 2018, I received a phone call to say the results were back. I spoke to the rheumatologist nurse who asked me whether or not I had started the arthritis medication yet. I confirmed I had not. The nurse told me it was good I had not started and that she did not want me to because my tests showed I had the hepatitis C virus. I did not know a single thing about it. I asked how I could have got it and she did not seem to know. I enquired whether it could have been from previous blood transfusions I had received in the 1990s. I was asked to provide the dates of my transfusions and to come in to chat about my diagnosis as soon as possible. However, my grandson was ill in A&E at the time I received her phone call and it all felt a bit surreal to me. I did not have time to really consider my diagnosis with hepatitis C because he was more important to me.
21. The phone call from the rheumatologist nurse advising me of my diagnosis came late on a Friday. This meant I did not have an opportunity to obtain further information. A diagnosis like this should not have been given over the telephone. It would have been best if the nurse had stressed the need to delay taking my arthritis medication and ask me to attend an appointment as soon as possible. I could have then been informed of the diagnosis face to face and had an opportunity to ask further questions.
22. I was diagnosed with hepatitis C two days before my birthday. I had lots of plans for that weekend, but could not focus. On Monday **GRO-C** 2018, I tried to telephone the nurse and could not get through. Despite this diagnosis, no one had tried to contact me to provide me with any further information. I emailed the rheumatologist nurse and she said there were no appointments available to talk about my infection with the hepatitis C virus.
23. Over email, I explained I had an existing appointment at University College London Hospital (UCLH) for an endocrinology matter and queried whether I could speak to someone about my hepatitis C when I attended. The rheumatologist nurse said she would see what she could do. I attended my endocrinology appointment and met with an endocrinology nurse who had no knowledge of hepatitis C. She had to

telephone a few people to find out what to tell me. I had further blood tests to find out my genotype and viral load. I did not understand what these tests were for. The endocrinology nurse then told me Professor Rosenberg at Royal Free Hospital would see me. He worked at UCLH but held his hepatitis clinics at Royal Free.

24. After the second blood tests were taken, the rheumatologist nurse called me to tell me I no longer had hepatitis C and my body had cured itself of the virus. I asked how this was possible and she said some people are able to clear themselves of the hepatitis C virus. The next time she telephoned to tell me she was sorry and this was not true. I was still infected with the hepatitis C virus. This was a big bombshell, I had first been told I had hepatitis C, then that I had cleared the virus, only to be told I did actually have it. All in such a short period of time.

25. I had further blood tests ahead of my appointment with Professor Rosenberg and then more tests when I met with him. The types of tests I had were a liver function test, a liver density test, a CT scan and an ultrasound to ascertain the state of my liver. I felt lucky though, as all the results were fairly positive.

26. In February 2020, I had to have urgent scans and it has been discovered that I have an "oddity" within the blood flow of my liver. The doctors do not know what is going on and whether this will change so I now have to have regular six month liver scans going forward. Despite being given the all clear from hepatitis C I do not feel as relaxed about the state of my liver. I do not know if my liver was already damaged or whether the treatment has caused this damage. As a result I am back under the care of Professor Rosenberg.

### **Section 3. Other Infections**

27. I am not aware of any other infections.

28. Although not an infection, I have suffered from Crohn's since 1989 and I think if I had not been diagnosed with Crohn's, my hepatitis C may have been picked up sooner. A lot of my health problems were attributed to Crohn's prior to my hepatitis C diagnosis.

29. I also suffer from rheumatoid arthritis and celiac disease, although I do not know how connected these are to hepatitis C.

#### **Section 4. Consent**

30. When I was given my first blood transfusion the medical and surgical team at Colchester Hospital informed me there were no potential or real risks anymore in receiving the transfusion as the blood was now safe.

31. It was never discussed, I was never asked and no advice was given about what it meant to receive a blood transfusion. In those days it was doctors who made the decisions about what was being done. They did not discuss their medical plans with you. Doctors would just turn up in your room and tell you what was going to happen. I have learned doctors will hold information back from you.

32. I did not consent and was not informed I was being tested for the hepatitis C virus.

33. In April 1991, when I had emergency surgery on my perforated bowel, the surgeon said it was the worst operation he had ever had. Photos and videos had been taken to record the procedure. He asked my permission and obtained my signature for the photos and videos to be used for medical conferences and for studies in the United Kingdom and Australia. I even attended one medical conference myself and was asked questions about my experience.



## Section 5. Impact

34. After I was told I had hepatitis C my mind started working overtime. I was so scared about who else I may have given it to.
35. A few days before I was diagnosed I had cut my foot and there was a massive pool of blood on the floor. I was looking after my granddaughter at the time and my daughter came over and had to clean up the blood.
36. Two or three days later my other granddaughter cut herself on the same place I had cut my foot on. Once I was diagnosed I was so stressed that she might have caught hepatitis C from that event. She was only four years old and had to go get blood tests done. We had to wait several weeks to find out whether she was clear or not but luckily she was. My husband and my daughters all had to get checked and thankfully they were all fine. I was the only one. I am so glad I had all my children before the transfusion, otherwise things could have been very different.
37. I have missed out a lot on my children growing up. My parents live in Wales and I find that a very difficult journey. I can only drive locally because of my legs. Recently I had to drive and I could not get out of the car after because my legs had seized up and were in so much pain. I literally had to drag my legs because I could not use them. We once had to make a six-hour journey to see my dad who was ill in hospital, but since then I have not been to Wales because it is just too much for me.
38. I feel fed up with hepatitis C. It is another illness I have to deal with and another burden on my family. They are very good to me, but that is how I feel. Hepatitis C has answered a lot of questions and explains thirty years of continuous illness. However, it is very frustrating to have to deal with. I feel physically and mentally weak and my husband has to deal with a lot. He finds the paperwork and the way I am treated at hospital very stressful. It also affects my daughters as they also worry about me a lot.

39. Some members of my family have reacted very negatively to my diagnosis and it makes me think that if members of my own family have had these reactions, what would people outside of the family say?
40. I still worry when I think about an incident that occurred before my hepatitis C was diagnosed. I was in hospital and I had been on a drip. Due to pressure from some swelling the drip came out and there was blood everywhere. I recall it was not cleaned up for a few days and the doctor who came to fix it did not wear gloves and seemed very blasé about it and the associated risks.
41. I threw all the razors and toothbrushes in the house away after I was diagnosed. I never drank much anyway and after finding out I had hepatitis C I ensured I reduced my drinking even more.
42. I do not feel up to socialising much and I find it difficult to speak to friends about my health issues. I told my closest friends I had hepatitis C but I do not think they knew what it was. One person I told thought it was just like a cold or flu so after that I decided not to explain it. This past year I have spent three to four days in hospital every single week. My friends do not know about this and I do not wish to go into it with them.
43. Mainly because of my arthritis, I do not see many people. I cannot walk very far and it makes me feel inferior to others who work and live active lives. I do not feel as though I can contribute as much. I have missed out on the community because I have always been withdrawn because of my illnesses.
44. I cannot partake in any hobbies, I used to make wedding cakes. I cannot pick things up so making cakes became very difficult. I even find using a mobile phone hard because my fingers are not very straight.

45. I was studying to become a dietitian. I had started my course and then due to my illnesses, the surgeries, and unknown to me at the time, my infection with hepatitis C, I was too unwell to return to university to finish the course. I have either always been in hospital or had to rely on other people to stand in for me. I have never been able to work properly and I have been told not to because every time I did try I ended up in hospital for months. I have always had to work around my medical issues and this has been a continuous strain on my finances and time.
46. I have had to go for so many scans and check ups at hospitals. This has sometimes meant an appointment at one hospital has resulted in a delay with an operation I have had scheduled at another hospital. I feel like I have been going backwards and forwards between hospitals for years and the entire time I have had to pay for all the travelling. It costs me at least £40 each time I go to London, which really adds up over time.
47. Before I was ill I used to be so organised and now things are falling apart. I have lost the ability to remain focused and organised. Sometimes I forget conversations or dates and it is very frustrating. This started in my early thirties before I knew what was wrong. I was tested for early on-set dementia because of it. I now understand that people with Hepatitis C have brain fog which to me means things are sometimes hard to recall. For example, I had a car accident a few years ago. I had to get a few treatments done because of it and I really struggled to recall these to the solicitors for my claim I was making. I was pulled up about that. If there are too many things going on at once I will completely forget something. I still have days where things are foggy. I had to actually go and learn strategies to help me with my memory.
48. Since my second transfusion I have not been able to tolerate milk and I wonder if this is a result of the hepatitis C.
49. I told my dentist I had hepatitis C and he was very understanding and thanked me for telling him. I do not know how related my dental problems are to hepatitis C or my other medical issues. I began experiencing problems with my teeth when I was in my thirties. I have now lost a lot of teeth. I would go to the dentist because of a

toothache and my teeth would often break or easily come out. I do not have gum disease and my dental hygiene has always been good so my dentist could not understand what was causing it.

50. I do wonder about the long-term effects of the hepatitis C treatment. I still feel really tired and my joints regularly flare up. I struggle with tiredness every day, I cannot ever sleep enough and sometimes I suffer from pain in the middle of my chest that lasts for several hours.

51. I feel that there is a stigma associated with hepatitis C. When completing my EIBSS application, I had to fill in a form saying whether I had my ears pierced, if I had any tattoos or if I had ever taken recreational drugs. I have my ears pierced, but have never had a tattoo or taken drugs. I feel this highlights the stigma attached to hepatitis C. The fact being infected with hepatitis C was out of my control makes it hard. I have to keep reminding myself it was not my fault.

#### **Section 6. Treatment/Care/Support**

52. After I was referred to Professor Rosenberg I had to wait about a month, until June 2018, before I saw him. I contacted the rheumatology nurse several times for updates before my first appointment with him, but all she could do was point me in the direction of the Hepatitis C Trust.

53. Before I spoke to the Hepatitis C Trust I was completely in the dark about hepatitis C. After speaking to them, they informed me about the process I would be going through over the next few months. They were very helpful and informative, especially Samantha May of the trust. They said the way I had been told I was hepatitis C positive was very unprofessional. I should have been sat down and told in person and not over the phone. They spoke to me about what I should expect and what tests needed to be done.

54. When I found out I had hepatitis C I was also having problems with my Crohn's disease and I needed bowel surgery. I was told I could not have the surgery until I had cleared the hepatitis C. I wanted treatment the day I was diagnosed. When I saw Professor Rosenberg he said because I had already had the virus for 28 years I was unlikely to come to any harm. He seemed to have the opinion that because I was female and my lifestyle was not a bad lifestyle, there was no rush to start the treatment immediately. Instead, I should go ahead and have the bowel surgery first. I felt like the NHS had given me this illness and now the NHS was also deciding when and whether I could receive treatment. That first meeting with Dr Rosenberg did not go as expected. He did not understand I wanted to clear hepatitis C as quickly as possible. He felt none of the rush and urgency that I did. Looking back now I understand why he made the decision to wait. However, at the time I felt he was keeping me waiting because he could. My subsequent meetings with Dr Rosenberg have been very different to the initial meeting. He has been very supportive and understanding since this time and has helped me a lot.

55. I think patients need to be given more information about their illness at the time of their diagnosis. If I had known more, I may not have come away from that first meeting with Dr Rosenberg feeling as stressed as I did. He was doing his job, but he did not know how little I knew and I wish he had asked the question about how much I knew at the first appointment. It felt like a misunderstanding on both parts and going forward it has not happened again.

56. The surgeon who was to carry out my bowel surgery said he did not want to perform the operation until I was cured of hepatitis C. He wanted me clear of hepatitis C before he would discuss dates for the surgery. I was meant to have the surgery in or around May 2018, but it ended up being delayed to October 2018 to allow me to have the hepatitis C treatment first.

57. Professor Rosenberg prescribed Maviret for my hepatitis C treatment. I underwent an eight-week course of Maviret. It started in July 2018 and finished in September 2018. The first 24 hours after taking it I felt absolutely awful and my whole body hurt. I had a temperature, brain fog and I could not focus or move. I wanted paracetamol at night because I felt unwell, but I could not move to get it. I did not

know how I was going to keep taking it every day for eight weeks. After the first night, I phoned the hospital and the nurse told me to persevere with the treatment. I was told to take paracetamol with the Marivet as I went to bed so most of the side effects would occur as I slept. I felt rough for the first seven days of the treatment and after that it got better. I still felt tired and headachy and sometimes a little spaced out, but the more I took the better I felt.

58. The UCLH only informed me of the tests and basics of the hepatitis treatment. It was the Hepatitis C Trust who provided me with the most assistance and information on the treatment, symptoms and long term effects of hepatitis C. I personally had to google to find the trust's details. I think if the hospital does not have time to provide detailed information, an organisation like the Hepatitis C Trust's details should be passed on so more information can be provided by a service who has time.

59. After my treatment I mainly dealt with Professor Rosenberg's specialist nurse Claire Smith, she became my main point of contact and still is today. Both have always been there to give me the information and support I needed at the right time.

60. Prior to the date of my bowel surgery, I had advised the hospital I had cleared my hepatitis C. I was scheduled to have my bowel surgery first thing in the morning, but because of my hepatitis C, I was told they might reschedule me to the last surgery of the day despite me telling them I was clear. They said the hospital had to do this because of the risk, even though I was cleared. This made me feel really anxious. Even today, in terms of having surgery a stigma still exists.

61. On the day of my bowel surgery, I was ready to go. A couple of hours prior to surgery, the private hospital I was at wanted proof I had been cleared of hepatitis C. They said they would not let me in the operating theatre without seeing copies of my latest blood test results showing my viral load had decreased. I desperately contacted Royal Free Hospital to try and get the information needed. Claire Smith helped me get copies of my blood test results to the hospital at the last minute.

This should not have happened. I have since found out this is illegal and they could have operated on me without me having to provide proof of treatment.

62. On 8 October 2018, my bowel became blocked and I had to call an ambulance. I carry information about all my illnesses and medical history with me to be up front and I include hepatitis C. When the paramedics saw this they would not give me any pain relief in the ambulance. I usually receive morphine at my house before I am taken in the ambulance and also at Broomfield Hospital. On this occasion, the ambulance staff told me they did not have any morphine, even though they did. The only reason I can think of that they would not give it to me is because they thought I was a drug addict. When I got to Broomfield Hospital I was left in a room and the gas and air were taken away from me. There was a lot of whispering behind my back and arrogance towards me. Everyone's attitude towards me was very cold and disrespectful and they would not look at me. I had terrible treatment from everyone. Even when I got to the hospital the nurses would not give me any morphine despite being in so much pain I could not talk. When I was finally given some, it was in one huge dose and not at all how it is normally prescribed. I think this is because the nurses also thought I was a drug addict. I could not believe this was how professional medical staff were acting. The ambulance came at one o'clock in the morning and I did not get pain relief until five or six o'clock in the morning because of the ambulance and hospital staffs' opinion of me.

63. One of the nurses at the hospital was going to treat me without gloves and I told her she should wear them. I asked if she had seen that I had, had hepatitis C and she told me very abruptly that she knew. I had just been cured of hepatitis C and did not want someone giving it back to me. I really did not like her attitude.

64. I was disgusted at how I was treated and made a complaint against the ambulance team and the staff who treated me at the hospital. As a result, the hospital suspended one of the agency nurses. I was told I would get feedback as to what other steps were being taken with the permanent staff, but I never heard anything further. In relation to my complaint against the member of the ambulance staff, I received a visit by a man from the ambulance service. He apologised, but said he

was not going to speak to anyone who was involved in the incident. He wanted to close the case. I said I wanted the matter investigated and the staff member involved spoken to. I later received a letter saying he was not going to speak to the person so I made a formal complaint. The case was closed and I was told if I was not happy with the care I was given, to take it up with the ombudsman. It has been so long winded and I do not want to take that path at this stage. I do not feel the ambulance service or hospital took my complaint seriously.

65. I have never been offered any psychological support. I think the doctors should inform people like me of the counselling options available at the time of diagnosis, because it was a huge shock at the time.

### **Section 7. Financial Assistance**

66. I applied to EIBSS in September 2018 after the rheumatologist nurse at UCLH told me about the scheme. I filled out part of the application form and my General Practitioner ("GP") filled out another part. He has been my GP since 1987 and wrote a letter supporting my application. Then I had to take it to Professor Rosenberg at Royal Free Hospital and everything was processed and submitted.

67. In November 2018, my application was accepted and I finally received my first payment just before Christmas in 2018. I received a lump sum and I also receive monthly payments and a winter fuel allowance.

68. I am currently going through the process of trying to claim for additional allowances because of my arthritis. I have been given a letter by Dr Davies, an arthritis specialist at Broomfield Hospital to support my application. Going through all the paperwork is stressful and I feel like I always have to prove that something is actually wrong.

69. I can claim for extra monthly payments if I can prove there is an on-going effect on my life. I am currently only eligible for the secondary monthly instalments. However the amount I receive will increase if I can prove I have suffered and I am still



suffering. None of my doctors understand the difficulties I have had over the years so I have had to give everyone the full picture over and over again.

70. It has helped to be awarded these payments. It takes a bit of the worry out of me having to pay for travelling back and forth from hospital appointments and not being able to work. I do think they should back date payments from the time a person is infected or diagnose when the impacts begin. It impacts my entire family financially. My husband runs a business and we had a mortgage. It has been hard.

#### **Section 8. Other Issues**

71. Since being diagnosed my biggest question has been about the media and the news. It was made very clear in the 1970s and 1980s that blood and blood products were infected with hepatitis and HIV but very little mention was made of the fact this was still going on in the early 1990s. The government knew that every person receiving blood within a certain time frame was at risk. I thought I was lucky because I did not need a transfusion until 1990. I thought there was no risk by that point. The doctors never expressed otherwise and it never crossed my mind that I would need to be tested. I already had a weak body and if I had known that receiving a blood transfusion in 1990 could make me more ill I would never have accepted it.

#### **Section 8. Other Issues**

72. There will be hundreds of people like me who had transfusions after the 1980s and need to know they are at risk. I do not feel like this period of time has ever been openly talked about.

#### ***Obtaining my medical records***

73. I have had great difficulty trying to obtain my medical records which I wanted to assist in evidencing what the NHS and government had done by giving me

infected blood and then not telling me about it for such a long time. When my GP was helping me with my EIBSS financial support application he also tried to get some documents to support my medical history. He was only able to get some letters from Colchester General Hospital archives. It is strange there are no records of the blood transfusions I received in 1990 before the 'cut off' period when blood was deemed to be safe. There are no theatre notes from the surgeries. However, there are theatre notes with records of the bloods I received after 1992. I think because I had a good relationship with my GP, he was able to help obtain them when I found it too hard on my own.

74. Colchester General Hospital has been very unhelpful. First they said they had trouble locating my medical records and then they said my hospital notes were destroyed because I was no longer a patient and they had been kept for over ten years. However, some of my notes were sent by Colchester Hospital to St Mark's Hospital with information such as dates and procedures redacted. This was the information I needed. Broomfield Hospital has been similarly difficult to request information from. I have found St Mark's Hospital the most helpful, providing me medical records from my time there as well as forwarding me any records they have received from Colchester.

#### **Statement of Truth**

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

Signed: GRO-C\_\_\_\_\_

Dated: 14.11.2020