

Witness Name: Ingrid Western

Statement No.: WITN2062001

Exhibits: WITN2062002-

WITN2062024

Dated: 14 August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF INGRID WESTERN

Section 1. Introduction

1. My name is Ingrid Western. I currently live in [GRO-C] I was born on [GRO-C] [GRO-C] 1960. My address is known to the Inquiry.
2. I moved to [GRO-C] from London in early 2015. I have an uncle who lives in Lincoln and an older sister, who lives in the United States.

Section 2. How Infected

3. In September 1987, I was diagnosed with stage 4b Hodgkins lymphoma at St Mary's Hospital, London. I had been ill for quite a few months by the time I received this diagnosis and it had metastasised to my bone marrow. I was immediately transferred to the Royal Marsden Hospital in Sutton and I started

chemotherapy treatment on the day I was diagnosed, as it was felt I was very ill.

4. I first had a total of 5 monthly treatments of CHOP chemotherapy. I do not recall how many, if any, blood transfusions were required during this first round of treatment. After this first round of chemotherapy, I was advised by the doctors at the Marsden that I was a high risk for relapse as the cancer was very advanced when treatment started. They suggested I have a new treatment of very high dose chemotherapy that would destroy my bone marrow and I would require a bone marrow transplant (using my own, now cancer free, bone marrow). My bone marrow was harvested and I then received this high dose of chemotherapy, which completely destroyed my own existing bone marrow. This was in June 1988 at the Royal Marsden in Sutton.
5. This left me with no blood being produced by my own bone marrow. I was told it should start working after a couple of weeks. Unfortunately my bone marrow had been hit very hard and did not recover as expected. This would be the beginning of a long period of regular transfusions of haemoglobin and platelets. I usually received 1 to 3 units of haemoglobin and 3 units of platelets, 2 to 3 times a week **WITN2062002**. This high dose chemotherapy treatment was the reason why I required such a large number of transfusions. My bone marrow was very gradually recovering but it took over 2 months for my blood counts to reach the values I needed before I could leave the hospital.
6. After I was discharged by the Royal Marsden Hospital in Sutton my 3 times a week transfusions of blood and platelets continued at the Royal Marsden on Fulham Road in London. I was told each unit of blood or platelets contained blood from 6 different donors to make up one unit. I do not know exactly how long these regular transfusions continued for but I believe it was for a year, at the very least. My records show that I continued to receive transfusions regularly until at least October 1990. **WITN2062003**.

7. At no time was I told of any risk of being exposed to any infection or virus during my long period of transfusions of blood and platelets. I believe that at the time I did not have any other option but to accept these transfusions as my blood counts were still at dangerously low levels and it was felt that I would have died if I did not have transfusions.
8. As a result of these blood transfusions I was infected with the HCV virus. I am unaware of any other viruses I may have received. I received many blood transfusions during this time and it is not possible for me to know which transfusion contained the contaminated blood. It is my belief that I must have received many transfusions containing the contaminated blood, due to the large number of transfusions I required.
9. During that initial year of treatment in 1988 I was tested for antibodies to various diseases, including hepatitis. According to my records I tested negative for hepatitis of an unknown specification on 6 August 1988, and negative for Hepatitis B on 3 November 1988. **WITN2062004.**
10. On 9 February 1989, a liver function test was conducted. The consultant noted that *"her liver function is a little deranged and I am not clear as to why this is. We will be looking into it when she is next admitted"*. **WITN2062005.** As far as I am aware this was not followed up.
11. On 9 October 1989, tests were apparently requested for both Hepatitis B and Hepatitis C (HCV). The Hepatitis B test was done on that same day and came back negative. There is a note next to my HCV test request form that reads: *"This serum will be kept for 4 months. A second specimen should be submitted to the laboratory in 3 months' time. The paired sera will then be tested for the appropriate viral antibodies. (Hepatitis C antibody tests are being performed at Colindale on paired sample only. Hep C antigen test is not available yet.)"* **WITN2062006.**

12. At no time was I told that I was being tested for hepatitis. The fact that I was tested repeatedly seems to imply that there was awareness of the risk of blood transfusions and the need for regular testing to monitor if patients had become infected. However, I was never informed of this risk or of the tests being conducted, and I continued to receive blood transfusions during this time as indicated above.
13. I do not remember when I was told I had the HCV virus but it was when I had started being cared for by the Royal Marsden in London, so therefore I believe it was sometime in 1989. I was still having regular platelet and haemoglobin transfusions as my blood counts were still very low.
14. I was told by a doctor at The Royal Marsden in London, during one of my regular outpatient clinics, that my blood tests were showing irregularities in my liver function and that they were a result of a virus called non A non B hepatitis. I cannot recall the name of the doctor who told me (it was not my consultant). It may have not been at the same time, but I also recall that I asked a doctor about why the blood used for transfusions was not tested or treated (for the virus). I was told that they "only recently had found a test for the 'non A non B' Hepatitis virus but it was giving false positives so they were not using it". I realise this possibly does not make sense as a reason for contaminated blood being given, and these may not have been the exact words, but it has been 30 years since I was told and this is how I recall the event.
15. My GP records show that I first tested positive for HCV on 1 July 1988, **WITN2062007**, but I am not sure if this is an error. My records from the Royal Marsden Hospital contain a positive HCV test result from 15 January 1990, which makes sense as it is four months after the paired sample HCV test was requested in October 1989. The test results contain the notes "Chronic active hepatitis. Multiple transfusions". There is also a letter from several years later confirming I first tested positive in January 1990. **WITN2062008**. My records from the Royal Free Hospital state that I was first diagnosed in 1992, but note my abnormal liver function dating from 1989. **WITN2062009**.

16. I do not remember being given any information about the virus when I was diagnosed, but at the time I believed that was because there was not much known about it at the time (it was not even referred to as hepatitis C then). It was only much later that I heard any mention of earlier knowledge of the virus relating to transfusions. At the time I was under the care of the haematology oncology team and they were dealing with my ongoing chronically low levels of haemoglobin, platelets and white cell counts as their priority, not my liver function.
17. I did not feel that information was withheld from me but that was because I was not aware of how much was known about this virus at the time. As I understand it, finding out when the relevant people became aware of the virus is something the Inquiry is hoping to establish.
18. I do not have any particular views or issues about how the results were given to me. As I was having such regular blood tests to see if/when I needed transfusion, I believe it was inevitable that they would notice my liver function tests were abnormal.
19. I do not remember anyone from the medical profession advising me about the risks of infecting others. I believe I found out about these risks when I started reading as much as I could find about the virus and its effects. I was given more information about the risk of infecting others, including my husband, later when I was put under the care of the hepatology team at the Royal Free Hospital.

Section 3. Other Infections

20. I do not believe that I received any other infections aside from HCV as a result of being given contaminated blood.

Section 4. Consent

21. I do not feel that I was necessarily tested without my consent or knowledge, as the virus was picked up as a result of the many blood tests I received relating to my lymphoma and bone marrow transplant.

Section 5. Impact

22. I feel that the mental and physical effects of being infected with HCV are numerous and life changing. If I had not received contaminated blood I believe my life would be very different to the one I have now and my quality of life would have been far better. I have spent the past 30 years in and out of hospitals receiving treatments and having operations as a direct result of this issue.
23. Physically, I have very little energy virtually all of the time. My overall general health is complicated and I have good days and bad days. I have had cancer twice, 3 organ transplants and 2 brain haemorrhages. I have osteoporosis caused by early menopause and I fractured my C5 vertebrae in my neck a number of years ago in a horse riding accident. I have constant chronic pain in my right ankle, which I have been told may have been exasperated by HCV, and I have been advised to have an ankle fusion and also an ankle joint replacement (both in the right ankle) to fix the problem. I had a stress fracture in my right tibia last year simply due to an increased amount of walking, as a result of osteoarthritis. I had to have regular venesections in the early 1990s, to remove the iron in my body that had caused haemochromatosis- a result of all the transfusions I required following the bone marrow transplant. A venesection would involve me going to a ward or clinic room, where a unit of blood would be taken from me. These venesections occurred once every two weeks and went on for approximately a year. This regular taking of blood only added to the fatigue I already suffered from due to the Hepatitis C, yet I was trying to work and lead a normal life, so I would again have a period of going to

a hospital first thing in the morning and then going directly to work - only this time I was having blood taken, not given. I could not start interferon treatment with such high ferritin (iron) levels and these treatments were the way to remove the iron.

24. I suffer from anxiety and depression which have been attributed to my health issues.

25. I now have a complex medical history. I have a number of medical/health conditions, but I believe the following are a direct result of having received contaminated blood transfusions:
 - a. Cirrhosis, first noted in a biopsy in 1995 (**WITN2062010**).
 - b. Cellulitis
 - c. Haemochromotosis
 - d. Liver cancer
 - e. 1st liver transplant in December 2006 after diagnosis of liver cancer at Royal Free Hospital
 - f. 2nd liver transplant in September 2008 at Kings College Hospital after the first transplant failed due to rejection of the organ and recurrent HCV;
 - g. After transplantation, in 2010 I still had HCV, which led to cirrhosis of the new liver
 - h. Condyloma/HPV which cannot clear due to immunosuppressants
 - i. Twisted bowel - caused by adhesions from transplant surgery
 - j. I had a subarachnoid Brain haemorrhage/stroke in 2013 - cause unknown but the neurosurgeon said she could not discount that there could have been a connection
 - k. Kidney disease stage 3b - due to immunosuppressants
 - l. Ongoing liver/gastrointestinal problems - stones in pancreas and kidney and dilated bile and pancreatic ducts.
 - m. Anaemia and general fatigue

26. On three separate occasions I had interferon treatment in an effort to clear the virus. On the first two attempts (interferon only at the Royal Free Hospital in 1995, and combination interferon and ribavirin in 1997) the treatment was stopped after three months as my white blood cell count was low and no substantial improvement was seen. **WITN2062011.**
27. Later, in November 2010, under the care of Kings College Hospital, after my second liver transplant, I had a third treatment of pegylated interferon and ribavirin. I seemed to respond better on this 3rd attempt and a few weeks into the treatment the virus was undetectable so I continued the treatment, with an aim of continuing treatment for 52 weeks. Unfortunately I had viral breakthrough at week 48 so that attempt was in vain and stopped. **WITN2062012.**
28. I understand that ribavirin treatment may have been available as early as 1992. There is a letter from my consultant at the Royal Free Hospital to the Royal Marsden in 1992 noting: *It may be possible to treat her with ribavirin as this is a nucleoside analogue which has been known to suppress hepatitis C in a proportion of patients. We have obtained reasonable results in patients treated in a pilot study, and have now embarked on a placebo controlled study. It is difficult to obtain ribavirin through the NHS at the moment from this hospital, but I could make enquiries. Alternatively, Miss Western could be, if she agrees, entered into our trial of ribavirin shortly.* **WITN2062013.** However I was not offered ribavirin treatment until 1997.
29. While on interferon and ribavirin treatment, I had severe side effects including migraines, sensitivity to light, nausea, vomiting, varicose veins on my legs and painful injection sites. I felt generally unwell for such an extended period that it felt like I was not really having a life.
30. There was an information sheet provided to me in March 1997 before undergoing my second course of treatment which contained a list of possible side effects of interferon and ribavirin. However, while the sheet did explain that

patients might experience flu-like symptoms, it noted that the side effects were usually mild to moderate and “appear tolerable for most patients” and would “respond to cessation of therapy”. It did note that some patients have reported “changes in the retina (the light sensitive membrane of the eye)” but that this was extremely rare. **WITN2062014**. During my third course of treatment, it was noted by my consultant that I was “getting the normal side effect profile associated with chronic hepatitis C antiviral therapy. She is an old hand at this treatment and with an objective eye, she seems to be doing relatively well.” **WITN2062015**.

31. I was offered the opportunity to participate in a clinical trial of telaprevir and ribavirin around 2012. A letter from a clinical lecturer at Kings College to my consultant in November 2012 notes that “based on the recent results presented at the Liver Meeting 2012, there might be a possibility of compassionate use of other antivirals with less interaction with immunosuppressant therapy and slightly less severe side effects profile with potentially better response (GS-7977 or daclatasvir). We try to contact drug companies and regulatory authorities whether that might be other option to ‘cure’ HCV infection for Ingrid”. **WITN2062016**. However I declined this treatment for several reasons: the side effects were known to be very hard to manage, there was a risk to me due to my anaemia, and the treatment required a restrictive regime involving consuming large amounts of fat before each tablet that I was not sure I would be able to manage. Instead I chose to wait to be treated with direct acting antivirals, which became available in 2014.
32. In 2014 Kings College Hospital put me on one of the first treatments with the new Direct Acting Antivirals. I received 12 weeks of Gilead’s Harvoni (sofosbuvir and ledipasvir) and ribavirin treatment, **WITN2062017**, which seems to have finally cleared the HCV as I have been virus undetectable since mid-2014. **WITN2062018**.
33. In 2015, after clearing the virus, I was placed on a registry for patients who had cleared HCV, as part of a study sponsored by Gilead called “A Long Term

Follow-up Registry for Subjects Who Achieve a Sustained Virological Response to Treatment in Gilead-Sponsored Trials in subjects with Chronic Hepatitis C Infection". The purpose of the study was described as 1) to determine whether subsequent detection of HCV RNA in subjects who relapse following SVR, represents the re-emergence of pre-existing virus, the development of resistance mutations, or whether it is due to re-infection; 2) to assess clinical progression of liver disease; 3) to screen for the development of hepatocellular carcinoma". **WITN2062019**. I believe this study is still ongoing.

34. I never faced any difficulties in accessing treatments and I feel that I have been treated extremely well by the hepatologists who have treated me through the years. I have also made it my job to know what new treatments were being considered and my doctors were always helpful in trying to get me on the best possible treatment options.
35. There was one incident in 1995 in which I waited over five months for a liver biopsy, which was required before starting my first course of interferon treatment. I followed this up with a letter to the hospital **WITN2062020** and I was subsequently admitted for the biopsy.
36. I do not feel that there are other treatments I should have been offered.
37. As you may imagine, the number of serious conditions and treatments I have received in an effort to keep me alive have taken a toll on me physically and mentally. Having said that, I am extremely grateful to all the workers in the NHS who have done such a wonderful job in keeping me alive.
38. The HCV virus causes fatigue and generally constant tiredness, making day to day activities more difficult. In the end, I had to stop working after the liver cancer diagnosis and this has obviously had an effect on my quality of life, and ability to lead a normal life.

39. My partner, and later husband, found my deteriorating health and inability to lead a normal life difficult to live with and we were divorced in 2006, just before I received the diagnosis of liver cancer and subsequent transplant. This was a very difficult and traumatic period in my life.
40. I believe that all of my health issues, including HCV, probably had an effect on the breakdown of my marriage. When I first met my ex-husband in 1990, I was relatively well and able to lead a normal, active, secure and happy life. My ex-husband found it particularly hard to deal with my interferon treatments and the physical and mental effects that interferon treatment causes - the constant flu like symptoms, depression and overall unpleasant side effects of the treatment. The HCV virus caused fatigue, apathy and emotional changes that eventually changed me and I was no longer the person I had been when we married.
41. I realise that I have been well taken care of and many other people have not been as fortunate as I have been. Nonetheless, my quality of life is not great. I am lucky in that despite all my medical conditions I can still do a great many things physically and have not been left incapacitated. However, my energy levels are low and I have a great deal of difficulty in finding the motivation to do things which I am physically able to do. I have become isolated and no longer socialise well and do not have the desire to do most of the things I used to do up until the time of the first liver transplant. I have developed anxiety and depression and I feel, to a certain extent, that these mental issues have done more to damage my quality of life than the physical issues.
42. As I have stated, I feel that since I was infected I have received excellent care from the many different specialists I now see on a regular basis. However, the sheer number of conditions I have been left with have meant that dealing with my medical conditions takes up a great deal of my life and has become something of a 'full time job'.
43. HCV has also affected my family. Initially, after my infection, I was able to live normally and travelled often, including regularly visiting my parents, who lived

between Germany and Florida. However, shortly after my first liver transplant in December 2006, both my parents passed away from separate causes in early 2007. I was suffering from rejection of the first transplant and was not at all well, and spent much of the time in The Royal Free Hospital. Unfortunately I was not well enough to travel and so I did not get to see either of my parents before their deaths.

44. My father had dementia and my step mother had become suddenly ill and was in a coma. When my father died in Germany at the end of GRO-C 2007 I managed to travel there, as I was executor of my father's will and had to help my sister with his affairs and to arrange and attend the funeral as my step mother was in a coma. This was a very difficult period for me both mentally and physically as I was dealing with organ rejection and the death of both my parents, all in the space of a few months. To make matters worse, while I was in Germany attending to my father's funeral, my step mother passed away - meaning arranging and attending another funeral. Unfortunately I was very ill on the day of my step mother's funeral and was unable to attend. I was devastated.
45. My relationship with my sister deteriorated greatly during this time and to this day is fractious and strained. She finds my medical and physical and mental difficulties very distressing and she often feels guilty and helpless that she cannot do more for me.
46. Approximately 20 years ago my ex-husband and I bought a plot of land in Costa Rica with the intention of moving there within the next 5 years. I went there on a number of occasions and started to talk to builders about building a small house on the land - we even got as far as having plans drawn up. I had met someone there and she had an equestrian centre near the beach and we arranged that when I moved there I would start up a horseback riding section of the centre, for trekking and riding on the beach. This was my lifelong dream. Unfortunately my health began to deteriorate, and by 2006 my husband and I

were getting a divorce and my HCV had caused liver cancer and my first liver transplant. My health and personal situations have obviously changed greatly since that time and I require regular and constant follow up care, meaning that I could now never live in another country, and certainly not in Central America.

47. I am so grateful for everything the NHS has done for me over the years and if I lived anywhere else I am certain I would no longer be alive. However, the lymphoma that initially caused so many of my problems has never returned and therefore I cannot help but think that if I did not receive contaminated blood I would now not have most of the mental and physical problems I have, and I would be living a very different life.
48. Until my first liver transplant I had a happy, busy social life working in the music industry. However, that changed immensely after the first transplant. As I was rejecting the organ, I was very ill and spending most of my time in bed - either at the hospital or at home. I was rarely well enough to go out and I did not want people to see me so ill. I stopped seeing people and was virtually housebound until I received my 2nd transplant 2 years later in September 2008. A long period of recovery followed, and I was again spending most of my time in a hospital bed, or occasionally at home. Recovery was difficult and obviously I still had the HCV virus which left me fatigued, lethargic and depressed. I became isolated and had periods of time when I rarely left the house for weeks. I never knew if I would feel well enough and therefore stopped making plans to see friends. This long period of isolation left me with depression and anxiety, and I did not have the energy or motivation to engage in any sort of activity.
49. I suffered a subarachnoid brain haemorrhage in 2013 and my mental health became considerably worse. Things have now improved somewhat but I still have a tendency to isolate and have energy problems and lethargy caused by my chronic anaemia and cirrhosis, caused by the recurrent HCV virus after the 2nd transplant in 2008.

50. Personally, I have never felt that I was ostracised or treated badly as a result of having HCV. Ironically, the only time it became an issue was when I applied for a position in the fundraising office for the Royal Marsden Hospital in Fulham and was told that the fact that I had HCV might mean I could not be employed by a hospital. Eventually common sense prevailed when it was realised that I would pose no threat to any patients by working in the fundraising department and I was given the position in the fundraising office.
51. I was relatively healthy for the first 18 years after being diagnosed with HCV and managed to sustain regular work. However, I was still suffering with bone marrow problems and needed regular medical treatments. I was treated with a great deal of compassion while working for Sony Music and Universal records, who were very understanding if I needed time off. Sony music were particularly kind to me, and when I needed the regular transfusions they allowed me to go into the Royal Marsden Hospital 3 mornings a week for transfusions and I would then take the bus to get into the office to work the rest of the day. I believe this gave me a focus and helped me keep a positive outlook throughout.
52. In 1992 I took the position at the Royal Marsden Hospital as I wanted to do something to thank the hospital for saving my life (although ironically, this is where I received the contaminated blood). After the Royal Marsden's fundraising appeal reached its goal, my position was closed and I was without employment. Early in 1993 I started my own business; an events production company working mainly in the music, publishing and fashion industries. This worked well as it enabled me to schedule work around any necessary medical treatments or appointments.
53. Although I was often tired, I was able to work, socialise, travel, and get married in spite of the fact that I was ill and required many different hospital appointments. I was managing to balance life, work and health issues until

things finally unravelled when I developed liver cancer in 2006. I had to close my business in late 2005 and have not been able to work at all since 2006.

54. Obviously not being well enough to work has had an impact on my income. My business was reasonably successful and provided me with a good annual income until I had to close it in 2005. My divorce was finalised towards the end of 2006, shortly before my first liver transplant. Due to the divorce, I had to sell our property, providing some finances for me to survive on, but I had no income. I was not eligible for any income support as I had the funds from the sale of the property. This was 2007 and at that time there were no financial schemes to support victims of contaminated blood until the introduction of monthly support from the Skipton Fund in January 2011.

Section 6. Treatment/Care/Support

55. I faced a very difficult treatment obstacle in 2007. At the time, I was a patient at The Royal Free Hospital under the care of the liver transplant team. My body had rejected my first transplant in December 2006 and I was told by the team at the Royal Free Hospital that I would be re-transplanted. I waited for a suitable organ, and I waited. I became very ill, and then in September 2007 they told me they had changed their mind and would not be giving me a second transplant. They said that it would be a 'waste' of an organ as it would just get infected again by HCV - although that was always the case if someone had HCV. Then one day they simply told me to go find a hospice (to die in).
56. Fortunately I happened to have a friend who is an oncologist and he said that what they had done was not right and I should try to get in to see the team at Kings College Hospital - which I believe has the best liver unit in the country. I was seen by Dr Agarwal in hepatology, and he was very shocked at what the Royal Free had done to me and after assessing me, he agreed to take me on and to re-transplant the rejected organ. This was towards the end of 2007 and I was again, very ill at the time. Unfortunately, there were problems finding me

a suitable liver due to the fact that I had lost so much weight, but finally in September 2008 I received a call saying they had a liver. It was not from a heart beating donor and therefore I was told it was not the best possible option, but by this point I was extremely ill and so they did the transplant. This second liver was immediately re-infected as the HCV was still in my body.

57. No counselling or psychological support has been suggested or offered to me. The only time I saw a psychiatrist was one appointment to put me on antidepressants to deal with the depression caused by the interferon treatment. Unfortunately the antidepressants did not help in any way.
58. In 2007 I was offered a place in a support group for people on the waiting list for liver transplants. **WITN2062021**. I did not attend this as it was a long journey from my home and I already found it difficult to travel to hospital for medical appointments, given how unwell I was.
59. As I've mentioned, I have quite a few health conditions - not all are a result of receiving contaminated blood. But ultimately it has been HCV virus and the subsequent problems caused by it that have most affected my quality of life - both mentally and physically. I often feel that I am existing, rather than living a happy and productive life, and that I have lost purpose in my life.

Section 7. Financial Assistance

60. I was under the care of the Royal Free Hospital when I received my first Skipton Fund payment of £20,000 in January 2005 **WITN2062022**. I was a patient of Dr Patch on the transplant team, and he completed the necessary form I had to provide to receive that first payment.
61. I do not recall any particular medical professional at the Royal Free, or otherwise, informing me about any financial assistance. As I remember, it was something I found out by myself by reading as much as possible about HCV

and particularly about people who had received contaminated blood. I do not have any papers relating to my application for the first ex gratia payment of £20,000.

62. In June 2006 I received the application form from the Skipton Fund relating to the first stage 2 payment. The form was completed by Dr Patch at the Royal Free confirming that I had advanced stage of illness (cirrhosis, liver cancer or transplant) and I returned the form in 25th July 2006. I received my stage 2 payment of £25,000 from the Skipton Fund in September 2006.
63. In December 2006 I moved and did not notify the Skipton Fund. In October 2013 The Skipton Fund wrote to me to advise me that I was entitled to an additional 'top up' payment of £25,000 and that regular payments had been introduced in January 2011 **WITN2062023**. They first wrote to me at my old address, and then wrote to the Royal Free Hospital to ask them to forward the correspondence to me at my new address (I was under the care of Kings College Hospital by this time). I contacted the Skipton Fund when I received the letter and they then sent me the claim form for the stage 2 top up payment and back dated monthly payments. I completed the form and received the lump sum payment and back dated payments covering the period from January 2011, in October 2013. **WITN2062024**.
64. I am currently receiving monthly payments of £2,333.33 from EIBSS.
65. I had no obstacles in receiving the payments, once I was aware of them. At no point did anyone from the NHS, medical profession or associated organisations advise me of any financial support available to me, apart from when the Skipton Fund wrote to The Royal Free asking them to forward the letter to me regarding the stage 2 top up.
66. I do not recall any preconditions imposed relating to financial assistance.

67. Initially I felt that the two first payments, of £20,000 and £25,000 were not really sufficient, considering that at that time, those payments were to be the only payments to people who were infected, and the second payment only to people who had serious liver disease. I felt that the total amount of £45,000 would be insufficient for anyone to survive on for the rest of their life, in the event that many people would probably not be able to work again and therefore that amount was supposed to support the patient (and possible dependents) for the foreseeable future. It seemed a step forward when I heard that monthly payments had been introduced in 2011.

Section 8. Other Issues

68. At one point, sometime in the mid to late 1990s, I spoke to a solicitor who was dealing with a possible group action that would look into the contaminated blood issue. I believe the solicitor was based in Stanmore, North London, but I no longer have his details. When we met we discussed a number of issues but in the end he advised me against joining the group action. I believe he already had just over 100 people interested, possibly signed up. All the other clients were on legal aid but I did not qualify for aid as I had savings, so that left me at a risk of having to bear all costs of the possible group action, which he stated could, indeed, amount to a huge figure. This is why I was advised to not join. I did not follow the matter up.
69. Unfortunately, I do not appear to have any documents that would be relevant to the Terms of Reference. I never received any papers when I was given a blood or platelet transfusion - I would simply turn up at The Royal Marsden and either go to a ward or a treatment room, where I would be given the transfusion. As I was receiving such regular transfusions of blood and/or platelets 3 times a week (for at least one year) the hospital had become very accommodating to my needs. I would arrive at the hospital early, have my transfusion, and head off to work. I do have some documents that relate to the stage 1 and 2 payments I received from the Skipton Fund. I have recently had to move house

more than once and still have a number of things in boxes and it is possible that I may have some relevant papers in those boxes. But I think that is unlikely as I do not recall receiving any paperwork about how or when I was contaminated and my medical papers tend to focus on my current medical conditions, as well as conditions and treatments I have had that are not necessarily a result of receiving contaminated blood.

70. I can honestly say I do not recall when I first heard the phrase "contaminated blood scandal" or when I became aware that there may be a more sinister issue surrounding people contracting HIV and/or HCV from blood or blood products. Even when I became aware of the ex gratia payments being offered, probably in the early 2000s, I did not realise anything wrong may have occurred. Although I do recall feeling that the payments being offered were conditional in some way and that they should be accepted as some kind of final payments and to not be contested in the future, I still thought they were simply being offered to people who had been victims of an unfortunate problem that was not known about beforehand. It is only relatively recently that I became aware that there may be issues surrounding awareness of the risks of giving patients blood products or blood transfusions.
71. My hopes and expectations of the Inquiry is that it will fully and comprehensively address the questions as laid out in Sir Brian Langstaff's Terms Of Reference for the Inquiry. I hope the Inquiry will be able to establish what was known (and when it was known) about the risks of infection associated with blood and blood products imported from commercial organisations in the U.S. coming from high risk donors. I hope it will establish why potential safety warnings were ignored and plans to make the U.K. able to supply its own blood were scrapped. I would like to know if documents and patients' records have been lost or destroyed.
72. From things I have read, I believe that there is an indication that there was knowledge about infected blood and blood products being given to patients as

early as the 1970s. If this is so, why and how could I (and others) receive infected blood as late as 1988, which is when I became infected. Establishing a timeline is important to everyone, and I would like to know why I was infected in 1988, at the very end of the supposed window of infected blood being used and transfused.

73. I also hope that the Inquiry will give equal importance to the cases of victims of HCV, as it sometime seems that the focus of the contaminated blood issue has been looking mainly into the cases of haemophiliacs and their infection. Both groups have suffered immensely from receiving contaminated blood or blood products.
74. I hope the Inquiry will address what and when the Department of Health, the government, the NHS, drug companies, the medical profession and any other organisations involved in decision making, knew about the risks in relation to giving patients contaminated blood and blood products. I would like to know if other patients were warned beforehand about the risks, as was never done in my case.
75. On the most part, I feel I received good medical treatment, and especially from Dr Agarwal and the hepatology team at Kings College Hospital. However, I was never given much information about the HCV virus and various treatment options. Fortunately I try to be as involved and informed as possible about my health conditions and so I researched as much as possible about the virus, its effect and new treatment options. I believe this helped me get on to early drug treatment trials at both the Royal Free Hospital and Kings College. Kings Hospital were concerned about my second liver as it was becoming very damaged and scarred and they put me on one of the first trials of Harvoni, which ultimately cleared the virus.
76. I have not personally tried to obtain any of my medical records but I know that the solicitors at Leigh Day have obtained records from the Royal Marsden

Hospital, Royal Free Hospital, Kings College Hospital and my GP, some of which have been exhibited to this statement.

77. Finally, I sincerely hope that the inquiry will get to the bottom of how and why this was allowed to happen and to ultimately determine if there has been some kind of cover up about any elements related to the contaminated blood scandal, which has devastated so many lives.

Statement of Truth

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

Signed

GRO-C

Dated

14 August 2019.....