

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN1947001

Exhibits: WITN1947002-

WITN1947021

Dated: 18 July 2019

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF GRO-B

Section 1: Introduction

1. My name is GRO-B I am divorced, single and live alone. I am currently unemployed for health reasons. My date of birth is GRO-B. My address details are known to the Inquiry.
2. I have four children; three sons and one daughter. They are all grown up and flew the nest quite some time ago.

Section 2: How Infected

3. It was the morning of GRO-B I woke to excruciating pain. My GP was called by my neighbour who advised that I should go straight to hospital. He called an ambulance there and then. I went to Queens Medical Centre in Nottingham by ambulance and was admitted. I went to theatre that same day, I was told when I came around from the surgical procedure that had been performed that I had an ectopic pregnancy but in my ovary not in my fallopian tube. I was told that I had lost the baby and that I had to have a blood transfusion during the procedure. My ovary had ruptured and I was haemorrhaging internally. I recall that when I awoke from the procedure I was on a drip of blood. My

ANONYMOUS

medical records indicate that I was transfused with three units of blood on 23 February 1983. (WITN1947002). The blood unit numbers are:

- i. 844 701 D2 of A Positive;
- ii. 844 713 D6 of A Positive;
- iii. 844 671 D7 of A Positive.

- 4. I remember that the transfusion continued into the next day. I was told that the ectopic pregnancy could happen again if I got pregnant. At that time, I was married to my first husband and my name was GRO-B
- 5. I was not infected with hepatitis C as a result of a relationship with another person.
- 6. When I arrived at the Queens Medical Centre in Nottingham I was very sick. The staff (and I) knew from my blood pressure being so low that my life was in danger, I was bleeding internally. I did not know for certain that I would need a blood transfusion, but, I think that I had thought there might be the possibility that I would need one because just prior to me being taken to hospital in the ambulance my GP suggested that I may be bleeding internally. I was not told beforehand about the risk of being exposed to infection from the provision of a blood transfusion to me.
- 7. I was infected with hepatitis C as a result of being given blood.
- 8. I never felt like I recovered fully from the ectopic pregnancy. I always felt like I was lacking in energy; always tired. I kept going to my doctor and telling him that I was tired and that I just did not feel right. I remember that I always felt like I was coming down with something but it never fully materialised. I just felt rubbish all of the time.
- 9. I moved home and registered with a different GP; I continued with my visits to the GP surgery and remember that I repeatedly said that I did not feel right. The new

ANONYMOUS

GP took blood tests. I was told that my bloods were slightly off but there was nothing unusual in the results and that I should continue to have my bloods taken every two months. I think I went to the GP for years having these bloods done.

10. I remember that at one stage in 1994 my GP noted that my liver function tests were high. He sent me to Castle Hill Hospital in Cottingham to see a liver specialist.
11. On 27 June 1994, my consultant at Castle Hill Hospital wrote a letter to my GP noting that he had been told by the GP that my alanineamino transferase was elevated slightly at 44 and 60 IU/L. He further noted that "given the level of liver disfunction [sic] I think this could just be due to a post-viral hepatic disfunction. [sic] On the other hand with a history of joint pains I think we should rule out an auto-immune problem. Hence I have asked for some blood tests including hepatitis virology, auto-immune profile." (WITN1947003). The consultant then followed up with a letter on 12 July 1994 noting that I had tested negative for Hepatitis A and Hepatitis B. (WITN1947004).
12. However, he did not do any further tests. He instead asked me if I had ever had glandular fever; as I responded yes to this question, he said that this was probably the reason why my liver function tests were high and he discharged me. He then noted in my records, "I have reassured the lady that there is nothing at the present moment to be done actively in terms of treatment and her lethargy which is already improving will gradually disappear." (WITN1947004). The blood tests continued.
13. Some years later, I asked my GP for a second opinion because I wasn't feeling very well; I think that this was in around October 2004. My request for a second opinion took me to Hull Hospital where I saw a registrar in gastroenterology. I was actually sent directly to the infectious diseases clinic. In writing this statement now, I have no idea why I was sent straight to the hospital and to gastroenterology and not to any other specialist. None of this was explained to

ANONYMOUS

me at the time. I just knew my liver function tests were slightly raised. The registrar took at least a dozen or more blood tests and I was also sent for a colonoscopy.

14. In February 2005; approximately three months later, I was told by the registrar in gastroenterology at Hull Hospital that I had contracted hepatitis C. (WITN1947005).
15. Subsequently it was confirmed in a letter of 17 March 2005 from my consultant to my GP that it is possible I acquired the disease following my blood transfusion 25 years ago as I did not believe I had any other risk factors. (WITN1947006).
16. I was called into her office for an appointment and told that the results had come through and that she could confirm that I had tested positive for hepatitis C. I could not believe and still cannot believe that it took so long to find out the results.
17. I was absolutely devastated at the news. I knew what it meant. I had done a brief course on infectious diseases previously through my work, and had learned about hepatitis. I thought that I could die. At work, I had observed people who had become infected with hepatitis through alcohol misuse. I must point out that it was hepatitis as a general infection and not hepatitis C. I was aware that the infection had led to cirrhosis, liver disease and death for these people. As I drank very little and did not take drugs myself I thought I was different and that I would be ok in the end.
18. The consultant asked me if I had ever taken drugs intravenously, I told her that I had not. She also asked me whether I had ever had a blood transfusion. I told her that yes I did have one and when. She said that this was probably how I had contracted the infection. She said nothing more about the infection, and told me I would see the liver nurse and the liver doctor to get treatment. She explained that I would have to have a liver biopsy first to establish how bad my liver was and what treatment I could get. Nobody gave me any information about the infection. I recognise that I was in shock that day but I do not think that this has

ANONYMOUS

affected my recollection of things. I was not given any handouts or anything similar.

19. I was not given any information to help me to understand and manage the infection. At that time, I did not know the real significance of carrying it; what it could really do to me. I thought that my liver should not be so bad because I had not been a big drinker or taken drugs. Somehow this offered me comfort; I was able to distinguish my condition from those I had observed through my work. I never thought that it could be a death sentence. I think I was trying to be very positive in a negative situation. In a strange way, I did not connect the training that I was given through my work to my own hepatitis. I was not told that I would have to be monitored for the rest of my life. I was just told that I could try treatment to get rid of it. I was under the illusion that I could get treated and that I would be alright; that it would go away. I was never told that the treatment would only stop the virus being active; it would not remove the hepatitis infection. I had thought that the treatment would get rid of all the scarring on my liver but it did not. I later learned that it is the scarring that goes on to cause the liver cancer. I did not know at that stage how bad my liver was or what could happen to it. I did not realise the full extent of the damage that the virus could do. I know what I do now about it, through my own research. I had to go back to the consultants after I completed my own research to ask them for information and advice.
20. I think that there could have been handouts with information on it for me. It would have been so helpful to me if I could have been given a leaflet when I was diagnosed. I think that this should have happened. Given the delay in delivering the hepatitis C diagnosis to me, I think that there was sufficient time for the medical teams to gather all the relevant information together for me to understand it. I would have preferred a leaflet with full information on it over the verbal information I received. I was always told I would be alright and I believed it. This obviously was not correct.
21. I was told verbally in the consultant's office. I think that she dealt with it

ANONYMOUS

satisfactorily. I think that there should have been handouts provided to me at the time of the diagnosis, providing factual information about what the infection was and what would need to be done in the short and long term, for example, tests to establish how bad the infection was.

22. I have several letters from various doctors treating me which imply that I should have been tested and diagnosed with hepatitis C earlier. It was noted by my therapist at the Chronic Fatigue service on 8 March 2007 that "she has not received any counselling or emotional support and has clearly not come to terms with this diagnosis, which she did not receive until September 2005 despite being symptomatic since the blood transfusion." (WITN1947007).
23. It was noted by my consultant psychiatrist at Castle Hill Hospital in 2008 that I was "seen by Dr Nanda in 1994 with fatigue, which at the time was felt to be 'post viral'. Interestingly liver enzymes were abnormal at this time, suggesting that Mrs [GRO-B] has been infected with hepatitis C virus for some considerable time. She had a blood transfusion in about 1980, which was probably the source." (WITN1947008).
24. It was noted by my consultant physician at Castle Hill Hospital in 2010 that "Mrs [GRO-B] was actually referred to hospital in 1994 with "post viral fatigue"; although she was noted to have abnormal liver enzymes at that time, and serology was sent for hepatitis A and B, no one thought to test her for hepatitis C and she was discharged. (WITN1947009).
25. When I was diagnosed with the infection I was told that my husband and the two children that I had to him; after the transfusion, would have to be tested. I was given advice. I was told not to drink but this did not bother me as I did not drink much anyway. I was told to have protective sex even though it was unlikely that the infection could be transmitted through intercourse. I think I was told there was a two percent chance of transmitting the infection in this way. I was also told not to share razors or toothbrushes.

Section 3: Other infections

26. I was tested for HIV and hepatitis B and I have not contracted those viruses. I have been infected with hepatitis C only.

Section 4: Consent

27. Prior to having the surgery in 1983, I was not told that I might need a blood transfusion. Therefore, I believe that I was treated without my knowledge, consent and without adequate or full information being given. I have no idea whether I was tested without my knowledge, consent or without being given adequate or full information, but I do not think that I was. I had to have a blood transfusion during the third lot of treatment that I received for the hepatitis C in 2012. At the time, I assumed that the blood was given because I had become so unwell, but, I do not know for sure. I do know that I was not consented for it, or advised why I needed it.
28. I was involved in research called '*biobank*' prior to and after my hepatitis C treatment, which I knew about, and did consent to. Therefore I was treated for the purposes of research, in relation to the treatment.

Section 5: Impact

29. My hepatitis C has had a profound effect on my mental and physical health.
30. I have mentioned previously that I felt unwell from the time of the operation in 1983. I have been tired, and exhausted at times ever since. I know that mentally, I was aware of being more short tempered and frustrated at not being able to go back to how I was. I do not know if I was dwelling on the loss of my child. When I was diagnosed, everything made sense. I have gone on to get liver cancer. The infection has made me feel depressed. I have tried various antidepressants but they don't seem to work for me. I feel that this infection has taken over my life. I

ANONYMOUS

constantly think of what I would have been like and how my health would have been if I had not become infected. I think I would have been a relatively healthy person. Everything that has happened to me in the last 20 or 30 years has been in relation to my liver. I also suffer from brain fog.

31. I learned that I had developed liver cancer in November 2014. I have also been diagnosed with fibromyalgia and had to have my thyroid and gall bladder removed. I had a liver resection at Leeds Hospital on 20 March 2015 as I had developed hepatocellular carcinoma. I had a hepatectomy as a result which removed 60 percent of my liver.
32. I received ribavirin and interferon for the first time in 2005 from Hull Royal Infirmary and for around five months. It was stopped early as I had become too sick to tolerate it for any longer. My white cells were so low as a result of the treatment that I developed thyrotoxicosis and required a thyroidectomy. (WITN1947010). This treatment did not clear the virus.
33. I had the second lot of the same treatment in January 2010 from Sheffield Hospital and for a period of 48 weeks. I was looked after much better at this hospital. They were managing the effects on my white blood cells very closely and were providing me with medication to counteract the negative effects of the treatment. They also referred me to counselling as I was struggling with the psychological effects of the treatment. (WITN1947011). This treatment was also unsuccessful as the virus became detectable again 6 months post treatment. (WITN1947012).
34. Since the ribavirin and the interferon treatments did not work I had to wait for a new treatment to become available on the market. My hospital notes from this period indicate that while there were new drugs that would be suitable, it would take time for the drugs to be licensed and for the NHS to fund them. In addition, there was a question about whether I would be eligible for this funding once it did become available, because I did not have cirrhosis.

35. I had a meeting with my consultant about my treatment options in July 2011. The hospital notes from this meeting state "issues discussed include the imminent licensing of Telaprevir and Boceprevir; the NICE guidelines view that all patients with hep C infection should be treated; the view that even if NICE guidelines do regard PI with PEGIFN and Ribavirin as the norm for non-cirrhotic Hepatitis C she has already received a full course of standard of care and should therefore be a candidate for further treatment with a protease inhibitor. Discussion about funding – no guarantees but she is aware that the clinicians will push to optimise the chance of those getting funding for treatment with the new PIs in appropriate people, and she would seem to fall into that category." (WITN1947013).
36. My consultant physician noted in November 2011 that I was "keen to restart treatment with the addition of a protease inhibitor which should be associated with about 80% chance of sustained virological clearance. Though two of these are now licensed, there will be a delay before NICE report which will probably be April or May of next year. I don't know if the commissioners will fund this treatment before the NICE reports." He then noted (WITN1947014):

I have undertaken to write to GRO-B to see whether there is any chance that the local commissioners in GRO-B might provide a course of protease inhibitor on an individual patient basis and I will also write to a colleague in Nottingham to see whether they are doing any clinical studies of new anti-viral agents which might be another way to get the new agents – I would imagine that any such studies would have a protease inhibitor in the 'standard of care' arm.

37. In May 2012, my consultant virologist wrote to my GP that (WITN1947015):

In my opinion this lady's psychosocial circumstances have been such a challenge for her that the effect on her mood and psychological wellbeing is as much a consideration in putting her forward for therapy as is her liver disease. I have explained that the Commissioner's may well fund protease inhibitors for those patients who have got liver disease, but it may be more

difficult to argue the case to treat those patients whose liver disease is stable. Nevertheless, I think as an MOT we should support this lady's wish for treatment, recognising her commitment to therapy and total compliance with her previous regimen, and to that extent I will copy her clinic letter to Thea Williams, and Dr Jo Nicholson and the Hepatitis C Nurses, so that she can be entered on to a waiting list for triple therapy when it becomes available. We should know some further information regarding availability of the PIs within the next 90 days or so, as the business case has been put forward to the Commissioners, and we are waiting to hear how much funding will be sanctioned.'

38. In June 2012, my consultant physician wrote to my virologist that because I was a GRO-B resident, they would need the approval of my local authority to agree funding for my treatment and enquired further about this. (WITN1947016).

39. Eventually, I was asked if I wanted to go onto a new treatment which consisted of the ribavirin and the interferon combined with another medication called telaprevir. This started at Sheffield Hospital around October 2012. I had to come off the telaprevir after only eight weeks; I was unable to go to the full term of twelve weeks as I had become so unwell again. I was admitted to the hospital at this point and transfused with blood. I know that I was very weak at the time and could hardly speak. I assumed my platelets were so low that I needed a transfusion. The hospital contacted the pharmaceutical company who provided the telaprevir who indicated that I should continue with the ribavirin and interferon only, for a total of 48 weeks. This is what I did. This time, I managed to achieve a 'sustained viral response (SVR)', 6 months after concluding my treatment in April 2014 (WITN1947017).

40. I remember that during the telaprevir treatment, I had to take around 20 grams of fat derived from food, along with the medication. I was followed up for one year after clearing the virus to check that the SVR had not changed (WITN1947018). I also had a fibroscan to check the scarring. I was then discharged, completely. I was concerned that this happened; I expected that I would need to have a check-

up every six to 12 months. I also assumed that because I had 'cleared' the virus and did not have a lot of scarring on the liver, my health would improve. My health did improve, but only slightly. I did not feel so much of the brain fog and I did not feel so full of flu all of time.

41. I believe that I did not face any difficulties or obstacles in accessing treatment for the hepatitis C, other than the above delay in obtaining funding.
42. I do not believe that there were other treatments that ought to have been made available to me, but that were not made available. I have no idea if there were other treatments available to me. I do think that I should not have been discharged from the care of the liver team in 2014. I think that I should have been followed up by them on an intermittent basis.
43. Soon after the discharge I became aware of symptoms of bloating in the evening time and of a dragging sensation in my stomach, which I initially put down to muscle tear. It went on for a long time and so I visited my doctor to get checked over. I was sent to see a gynaecologist as a precaution. He examined me for a prolapse. I mentioned that my tummy was extended. He sent me for an ultrasound scan in November 2014 which confirmed that there were no gynaecological problems but, a mark on my liver was discovered which needed to be investigated further (WITN1947019). I was sent for another ultrasound scan the following week. I needed to have this second ultrasound scan with a dye put in me to see what the mark on my liver was. The mark could still be seen. I was not told it was cancer but I was told that I needed to be sent for a CT scan.
44. At around the same time I was seeing another doctor in the immunology and allergy clinic as I was suffering badly with hay fever. I had just finished a three year treatment for allergy to grass and I was waiting to go onto treatment for allergy to birch pollen. The doctor I saw in relation to the birch pollen treatment told me that he could not put me on it as I had liver cancer. I responded by saying that I did not know I had cancer, that no-one had told me. I assumed at that point that he had seen the results of the CT scan that I had previously been

ANONYMOUS

sent for. He immediately went away and tried to phone some people to find out why I had not been told. He did not get anywhere with this. I left his clinic and that was it.

45. There is a note in my records from Hull Royal Infirmary from a Mrs Pamela Parker on 3 December 2014 which refers to my ultrasound taken on 27 November 2014 and says "the patient is aware that there is an abnormality within the liver but I have not mentioned that I suspect this to be cancer." (WITN1947020).
46. I waited until I received an appointment with one of the liver specialists at Hull Royal Infirmary. I was told at Hull Royal Infirmary that I had liver cancer and that I could not be treated there, I was told that I would have to go to St. James's Hospital in Leeds for treatment. I waited and waited for the appointment. I phoned, every week, twice per week, to chase the appointment but the delay continued. This delay, and the fact that it was in breach of the hospital's targets for providing treatment, is mentioned in my GP records. A note from Hull Royal Infirmary on 7 January 2015 reads: "Referral to Treatment Target Date: 31/12/2014. Days remaining to meet target: -9. ****BREACH****" (WITN1947021).
47. Obviously at this stage I knew it was cancer and I was very scared and uncertain about what lay ahead. I eventually got an appointment in February 2015. I think this delay is outrageous and totally unacceptable. I was in a very bad way. I was very, very scared. My life was on the line. I am sure that if I had not persisted with the phoning that I would have been lost in the system. I can only imagine what happens to people who are not able to follow up like I did. It is my opinion that it was known that I had received the infection from contaminated blood and I believe I should have been fast-tracked to treatment and follow up as a result.
48. This whole thing happened through no fault of my own. I feel very strongly about the fact that I should have had six-monthly or annual follow up scans after being cleared of the virus. I think that I should have been regularly monitored; this could have avoided me developing such serious cancer and having to have the resection operation which removed such a large proportion of my liver. I wonder

ANONYMOUS

how many people who have died not knowing they had cancer, after being told they had cleared the virus.

49. The effects of the treatment were terrible, each time. After my first treatment I developed Sjogren's syndrome which is an autoimmune disease. The treatments made me feel like I was having a really bad and constant dose of the flu. I had shortness of breath, headaches, lethargy, brain fog, a loss of appetite and I was suicidal. I lost some of my hair.
50. It felt like I was having a constant battle with the treatment but it was made worse by the way I was treated by the liver nurse during my first treatment at Hull Hospital. I remember having to wait in the corridors on the gastric ward for my nurse to become available for me. There was no clinic for me to go to and wait in. When she was available, she took me into her staff room so I that we could have a consultation prior to her providing the prescription for the treatment. I administered the treatment myself. I was always scared of being truthful with her about the dreadful side effects I was experiencing because I was so worried I would be taken off the treatment. All I could think about was getting clear of the hepatitis C. I was desperately to finish the treatment; I needed to rid myself of the virus. It was all I could think about.
51. When I had the second lot and the third lot of treatments at Sheffield Hospital, my experience much better. There was a specialised clinic, there was more support; they provided a support group that I went to which definitely helped me to get through the whole experience.
52. When I went onto the telaprevir, my system felt like it was totally shutting down. It was completely different. I started to go into myself. It was like I was inside a bubble. I was in a really bad place with it. It felt like I had shut myself off from everyone. It was a very dark time for me. My husband at the time looked after me. I would not have got through it without him. I was living through a nightmare.
53. As I have mentioned above, I had a resection operation in March 2015 for the liver cancer. The loss of 60 percent of my liver has really disabled me in a lot of

ways. It takes several months for a person's liver to regenerate and although this has happened my liver is much smaller now and not the same shape. My bowel travelled to the space that my liver used to occupy which has created a diaphragmatic hernia. I had to see a thoracic consultant who told me he would be very reluctant to operate because of the seriousness of the operation and his concern that I would not be able to tolerate it.

54. The hernia means that I cannot lift anything; I cannot go to the gym or be energetic. I had to apply for a blue-badge. I can lift my shopping but it affects me if I do. The quality of my liver has changed. I have a ten centimetre cyst on my liver from the resection, I did have it drained once but it was so painful and the risk of infection was so great that I have to avoid having it drained again. I have to live with it. This cyst causes me pain and restricts my physical activity. The hernia and the cyst are connected. I realise that I will never be normal again. I wish I was normal. I wonder what I would be like if I did not have all of this. I am a very private person and do not really talk to people about these things. There are still a lot of people who do not know about this, I don't want to be judged, I don't want the stigma, and I don't want the questions. People are very ignorant about this. I realise that this further isolates me.
55. After I had cleared the virus, I recall having to attend Sheffield Hospital to have some treatment for my osteoarthritis; it was completely unrelated to the hepatitis C, or so I thought at the time. I was given the stickers for the blood tests; my stickers still had the hazardous warning sign on them. I had an argument with the orthopaedic consultant the hospital as I could not understand why they were still saying I should be treated as though I still had the hepatitis C. I refused to have blood tests until the hazardous sign was taken off. My view was, I either had hepatitis C or I did not. In the end they took it off but only after a lot of discussion had taken place.
56. I think that I did not feel the full force of the hepatitis C until I was diagnosed. I managed my symptoms up until then. When I was diagnosed, everything changed. Nothing was and will ever be the same again. My private life was

ANONYMOUS

- badly affected. When I was first diagnosed, I felt like my partner turned against me; he warned me that I had better not have infected his children. After this my libido was affected.
57. My children, when I told them, were hysterical. It was a very, very difficult time. They were scared, to the point of being almost paranoid in case they had or would become infected. I was frightened I could pass the infection on to my partner and my family. My family has seen me unwell a lot over the years and I have been unable to join in on family things as a result; I have been excluded from enjoying family activities because of my health.
58. I often used excuses to cover up for my illness because I did not want my family to get fed up with me and I did not want them to worry about me. I have not been able to look after my grandchildren as much as I would have liked because I feel tired all of the time. In terms of my social life, holidays became very difficult for me and insurance was something that made holidays impossible at times. My tiredness has prevented me from socialising with my friends on occasion. Given everything that has happened to me I find it difficult to move on into a relationship particularly because of all the medical history that I have.
59. The stigma that there is associated with hepatitis C began for me in 2005 when I found out that I had been infected. I remember that when I told my GP he said to me that he never would have thought that I would have hepatitis C, like the drug addicts that come to him who were '*the scum of the earth*'.
60. I had a nurse at Hull Hospital tell me once while she was taking my blood that I did not fit the picture of a drug user; someone who she thought could be infected with hepatitis C. She then asked me how I got it. A complete stranger was sitting in the next chair to me at the time, who overheard everything.
61. There have been many instances when I have come home and been in tears. I have seen exchanges between nurses who have wanted to avoid taking blood from me and who have only put on gloves and an apron when taking blood from me, when they have not from other patients. This has made me feel humiliated.

- There should be a standard approach for everyone. I also remember that at Hull Hospital, my blood card was placed into the bottom drawer of a cabinet which had the label 'HIV/ Hepatitis' on it. This cabinet was placed in a public blood waiting room where people waiting beside you could see the information on the label.
62. There were work-related effects and financial effects. Following my first treatment I had to give up work as I was too ill to do it. I never went back. I never told them why. I kept the hepatitis C private. It is no wonder that I did this given what has been said to me over the years. I did not want to have to face people's prejudices at work. I was lucky, my husband had a good job, but I did lose my financial independence including payments into my pension. I became wholly reliant on my husband for financial support.
63. I know that my partners, children and other family members worry about me. My children were so concerned when they found out that I had liver cancer and may have to have a transplant that they put themselves forward as possible live liver donors; to donate a section of their liver to me if they matched.
64. I would like to say that I consulted Dignitas after I was diagnosed with the liver cancer and before the resection operation. I made a very personal decision that I did not want to deteriorate in the ways that I thought I would before qualifying for any possible liver transplant. Doing this enabled me to take control of my own life and death. I was sure I did not want the government to control my death.

Section 6: Treatment/Care/Support

65. I feel it difficult to write about the difficulties and obstacles that I have faced in obtaining treatment, care and support because of my fear that my future treatment care and support may be negatively affected by what I could say.
66. I managed to gain access to a Hepatitis C Support Group at Sheffield Hospital which became a really strong support to me in my life.

67. I have also had some counselling. In relation to the counselling, my nursing friend could see that I was really struggling with everything that had happened to me. She wrote to the cancer clinic in Hull Hospital to see if I could access some counselling. I am glad to say that this resulted in me receiving counselling. The counselling only lasted for approximately three months. At the time it helped and I am grateful for having received it but I think I could have benefitted from having it for much longer. I think that for what I have gone through, it is something that should be offered and available to me to readily access when I need it.
68. I feel that I am living with a ticking time bomb and an uncertain future. As I am living with my illnesses, I worry constantly and get stressed and have anxiety about becoming sicker. There is no end to this. I feel I have this horrible contagious disease that I could have spread to others. I would like the opportunity to have ready access to support should I need it.

Section 7: Financial Assistance

69. I received financial assistance from Skipton and EIBSS.
70. The hepatitis C nurse advised me to make a claim to Skipton Fund in 2005, when I was first diagnosed.
71. I received a £20,000 payment in around June or July of 2005 from the Skipton Fund. In 2015 I received Stage 2 payments as I had developed liver cancer. These payments amounted to a one-off payment of £50,000 and an annual payment of approximately £14,000 which was paid quarterly. Now, I receive £18,432 per year, which is paid to me quarterly. I also receive a £531 annual winter fuel allowance. I get an additional household income payment; which is means tested, and amounts to a monthly top-up payment of £479.
72. As I have indicated, I was told to apply to the Skipton Fund by my liver nurse in 2005. I had to send in medical notes, along with an application form which was

ANONYMOUS

part-filled out and signed by my GP. The process was straight forward and resulted in a payment coming through to me quite quickly. When I developed the liver cancer, my consultant told me I could apply for Stage 2 Skipton payments, I was only given a year to 18 months to live then. I think I filled something out; my consultant filled out something else, signed it and sent it off. I received a response very quickly.

- 73. I faced no difficulties or obstacles in applying for and obtaining financial assistance.
- 74. There were no preconditions imposed on making an application or in being granted financial assistance.
- 75. I believe that the payments that are made are inadequate. They in no way compensate me for what I have had to go through.

Section 8: Other issues

- 76. There are no other issues in relation to which I consider that I have evidence which will be relevant to the Inquiry's investigation of the matters set out in its Terms of Reference.
- 77. There are no other documents which I have that might be relevant to the Inquiry's Terms of Reference.
- 78. I would like the Inquiry to find out who is responsible for this tragedy and to hold each person responsible to account. I would like adequate and proper compensation to help me to live as normal a life as possible. I think that the public should be made aware about the specific risk that attaches to receiving a blood transfusion; there should be more information made available about blood and blood products. I think patients should be consented properly.

ANONYMOUS

79. I have no concerns about the accuracy or completeness of my medical records. I think I was lucky enough to get them early enough. I had no trouble obtaining my records when I asked for them, when I applied for them they came quickly. I remember that when I requested them, it was at the time just before they were put onto computer.
80. I am choosing to not complain about my experiences with the NHS; especially when I had my liver re-sectioned. I could list a very long list of bad experiences but I do not want to because I am afraid of the possible consequences of doing so. I have to rely on the medical profession to look after me in the future. To put it mildly, my experiences could have been a lot better. I think a lot of it has to do with the stigma that is attached to the virus. My experience with the stigma that is attached to this disaster has been dreadful.

Statement of Truth

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

Signed:

GRO-B

Full name:

GRO-B

Date:

18 July 2019