

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0314001

Exhibits: NOT RELEVANT

Dated: 18 April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1959. I have been with my husband for GRO-B years but we have been married for GRO-B years, as we got married on GRO-B. We have two children, one of which is 19 years old and the other is 17 years old.

Section 2. How Infected

2. I was born with a harelip and cleft palate and as a result I underwent 23 operations from the age of 6 weeks old. The last operation I

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remember having, occurred when I was either 18 or 19 years of age and I had my top jaw brought out in line with my lower jaw which involved the surgeon taking bone from my hip.

3. It was after that operation that I became anaemic and received 4 units of plasma, which was just before hospitals started testing for hepatitis C. This was a planned procedure.
4. The procedure involved removing fragments of bone from my hip to my jaw and my mouth was clamped together with a brace for eight weeks to heal.
5. During the operation I lost a significant amount of blood and in the 10 days that followed I was not eating or drinking properly at all. After a series of tests they discovered I was anaemic and on 13 August 1979 I was given 4 pints of plasma via a blood transfusion.
6. After the operation and the blood transfusion I was discharged and carried on with life as normal. However in my 20's I found that I couldn't sleep through the night as I had always done before. Also I became intolerant to certain food and drinks.
7. I couldn't drink tea, coffee or tap water without feeling nauseous which was very unusual as I had not felt this way prior to the operation. This carried on throughout my life and still affects me today.
8. Prior to the blood transfusion I had always been very active, I taught an aerobics class and avidly visited the gym. However I noticed that I would feel completely drained and extremely tired with little or no activity so I had to stop attending the gym.
9. Thereafter I visited my GP and a series of tests were carried out to determine if I had any thyroid problems which they could attribute to

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my feelings of increased tiredness. The results showed that I had some activity in my liver and it was not functioning properly.

10. The doctor could not determine what was causing this activity in my liver and it was left alone at that stage. The only way they would have been able to know it was hepatitis C would be if they had specifically tested my blood for it or other blood-borne diseases.
11. I remember at one point in the late 1990's I wanted to donate my blood but I started hyperventilating when they inserted the needle into my arm and I couldn't go through with it. The doctor believed that I had developed a low pain threshold as a result of the numerous operations on my jaw in the past.
12. My husband is a GRO-B and the blood transfusion services would regularly contact him to donate his blood. So approximately ten years after the last attempt on my own, I told my husband that I would accompany him on one of his visits to the blood donation centre to try again in donating my blood.
13. In 2007 I followed my husband to the blood donation clinic which was done at the local town hall and explained to the nurses that I had previously tried to donate my blood ten years ago but I could not follow it through. They said they would monitor me and this time I was able to donate blood successfully.
14. Thereafter I received a letter from the Blood Transfusion Service in which they stated that they suspected I had hepatitis C in my blood and asked that I telephone them. I remember being distraught for about a week after that. I eventually telephoned them and got the news from the doctor.

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15. Upon contacting them they advised me to visit my GP for further tests to confirm if indeed I had hepatitis C and the results confirmed that to be true. I was very upset. (Tearful) It was like I was given a death sentence. I remember walking around in floods of tears all the time.
16. I was confused as to where I had contracted hepatitis C. I have never taken any drugs intravenously, I have never used or shared any needles or had any tattoos and I did not have multiple sexual partners.
17. These were the main ways I understood hepatitis C to be transferred to others but I did not do anything in my personal life of that kind. The only exception was I had my ears pierced but this was done in sanitary conditions with a sterile ear gun.
18. Prior to the hepatitis C diagnosis in 2007 I had some dental treatment and I was worried it came from the dentist surgery. I wasted quite a bit of money chasing that up as it proved unsuccessful. It was so upsetting trying to work out how I came into contact with hepatitis C and all the while I felt very dirty.
19. I was so worried that I may have passed it to my husband and our two children who were very young at the time. GRO-B
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20. GRO-BGRO-B I did not want anyone to find out as we live in a small village and I was scared that if people did find out they would think I was an ex-drug addict and would avoid all interaction with me.

Section 3. Other Infections

21. As far as I am aware I did not contract any other infections separate to hepatitis C and as far as I know I did not have any other infections.

Section 4. Consent

22. I knew that I would be given 4 pints of plasma as a result of being anaemic in 1979. However I was absolutely not made aware of the risks of infection prior to receiving the transfusion.
23. During the operation I had to sign a disclaimer to agree that the doctors could do whatever they needed to do in order to save my life.
24. However the blood transfusion came 10 days after the operation and I was mostly in a dazed or unconscious state due to the anaemia. I believe my mother consented to me having the transfusion.
25. I am not aware of whether there was any tests done on me for other reasons.

Section 5. Impact

Mental Impact of Hepatitis C:

26. After the blood transfusion I started to notice that I no longer felt like my normal self. I had low mood most of the time and I couldn't pick myself up whenever I felt down.

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27. At the age of 21 I tried to commit suicide by drinking dissolved tablets in a pint glass. Thankfully my friend came over that day and noticed how bad I looked and called my sister and they both took me to the hospital where I had my stomach pumped. I did not know why I did it and I remember feeling silly and upset and telling myself 'pull yourself together' afterwards.
28. When I was approximately 28 or 29 years old I was diagnosed with depression and I had sessions with a counsellor that lasted for at least five years. This all happened before I had children.
29. I still suffer from low mood today but most days I am able to hide it by putting on a front for the rest of the world.
30. From the point of diagnosis in 2007 onwards I was so scared of my own blood. If I cut myself at home I was insistent that I be left alone and no one come near me.
31. Also if any member of my family cut themselves I would put on rubber gloves before helping them. And if anyone used my toothbrush by mistake I would get very angry, but today I just hide it so no-one can use it.
32. I usually shaved my underarms and legs and if my daughter used my razor I would be furious with her as I did not want her or any other member of my family to be exposed to the risk of having Hepatitis C.
33. I can only describe myself as 'over the top' wherever blood was concerned. I would even separate my toothbrush from the rest of the family's so that they could not use it. It was a tremendously difficult time but that is all in the past now.

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Mental Impact of Treatment:

34. The mental effects of the treatment itself were that I was mostly in a mental fog. I was doopey and tired and I always felt like sleeping during the day. I was constantly frustrated with myself and I couldn't stop crying.
35. Unfortunately life had to carry on but I was unable to do so many normal day-to-day things. My eldest sister had to come and help me with day to day chores and my work.
36. My whole demeanour was to try and cover up what was going on. I went into a shell and kept myself to myself. I did not want to eat anything at all so I had to force myself every single day to do so. I lost 3 stones during the treatment.
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38. I was mainly worried about my blood being on my children but I think I dealt with it quite well given the circumstances. I remember when my daughter was 10 years old she use to get quite feisty and kick me in the leg and it would really upset me because I thought I am already being kicked everyday with hepatitis C.
39. During the treatment I continued to drive but at one point I was

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 and had an accident which I believe was a result of the treatment as I was constantly in a daze.

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40. Thereafter the mind fog became even worse and on one occasion I reversed my car into my husband's car. I also had little biffs with gates

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and walls so I stopped driving altogether as I felt I was a danger to others.

41. My sister had to drive me around towards the end of my treatment. It was strange because I was a farmer's daughter so I use to drive tractors and other machinery with no problems at all when I was younger but because of the treatment I could no longer manage it.

Educational Impact of Hepatitis C

42. By the time I was 19 years old I had undergone so many operations which meant I lost so many years at school so when I was infected I was already a 'lost cause' in terms of proceeding with further education. So I cannot say hepatitis C prevented me from pursuing academic goals.

Physical Impact of hepatitis C:

43. As mentioned in question 2 it began with an intolerance to coffee, tea and tap water. I had grown up in a pub environment and I use to work in a pub at the age of 21 but shortly after the transfusion I noticed I couldn't drink wine without having a tremendous headache.
44. I was a barmaid back then and the local customers would buy me drinks but I always had to decline. Not that I have ever been much of a drinker.
45. Shortly thereafter I discovered I could not eat certain foods I previously enjoyed. After learning I was now strangely intolerant to types of food, I spent a lot of money having private allergy tests, homeopathy treatments, blood tests and skin tests to find out why.

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46. Just before I was diagnosed with hepatitis C in 2007 I visited a private herbal practitioner in GRO-B I had been visiting as an outpatient and they believed there was something wrong with my liver but could not determine what the problem was.
47. At the age of 23 I noticed my hair was turning grey which was not a family trait at all. Since then I would visit my local hairdressers to dye my hair back to its normal colour and even though I was unaware of the hepatitis C at the time, I believe this was as result of it. I have dyed my hair ever since, even to this day.
48. I found that I could not use the normal dye without my scalp going red raw so my hairdresser at the time would use a different formula of hair dye for me.
49. Gradually I found the most normal, daily tasks difficult to cope with. I would have 8 hours sleep at night and go to the gym to teach my aerobics class during the day and return home feeling extremely tired which was unusual for me.
50. I have suffered with bladder problems since the age of 20 and this has recently been diagnosed as painful bladder syndrome. The doctors could not determine what was causing it but have linked it to contracting hepatitis C.
51. Painful bladder syndrome still affects me today and I am currently on treatment from Canada with the NHS for it as an outpatient. The treatment lasts for 5 months and involves pumping in a coating on the bladder.

Physical Effects of Treatment:

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52. I use to have very thick hair but once I began treatment for hepatitis C in 2007 my hair started falling out and became very thin. I mentioned to my hairdresser that I was undergoing treatment and that was the cause of my hair loss. She assumed I had cancer and I never corrected her.
53. This is because I always felt dirty having hepatitis C and I was so scared of anyone finding out so I just let her believe it was cancer as I felt people were more understanding and sympathetic of that.
54. The treatment for hepatitis C lasted for a year and during that time it would make my legs feel weak and crumple unexpectedly and I would reach for the nearest object to steady myself. I also suffered with nits in my hair and threadworms. I still suffer with threadworms constantly.
55. Halfway through the year-long treatment I fell down the stairs after my legs suddenly buckled and I went down on my back from the top of the stairs to the bottom. During the fall my back banged on the staircase all the way down and now I suffer constant pain in my lower limbs and back from trapped nerves due to a crumbling disc.
56. I went to my chiropractor and it was only a few years ago that they attributed the crumbling disc to the fall during treatment. It has cost me a lot of money to manage as I had to pay for the chiropractor sessions and accompanying treatment.
57. Currently I am on 100ml of gabapentin for my back pain which I take three times a day and will have to take for the rest of my life until I eventually have a back operation.
58. Whilst undergoing treatment for hepatitis C I lost 3 stone in weight and even though most days were terribly difficult for me with the side effects of treatment, I still had to run a business as a landlord in

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59. I should not have been driving during treatment but I had to as my children were aged 9 and 6 at the time and had all these after school clubs like swimming and I did not want them to miss out.
60. They were so active and always wanted to go out all the time and play in the parks which was very limiting for me as they were at that demanding age and I couldn't yield to them due to feeling run down all the time.
61. Progressively I became even more lethargic and didn't get much sleep throughout the night as a result of the treatment. I could not even load the dishwasher without feeling exhausted and I could not manage the school run so I would tell my children to join other parents in the neighbourhood who were taking their own children to school.
62. The treatment has had a lasting effect on my tolerance to some foods as I can only eat meat that is grilled with plain vegetables and has not been cooked in any sauces, so my food palate was and still is very restrictive.
63. I also cannot eat anything that has been cooked and placed in the fridge as well as most restaurant foods. If I do eat such things then I get severe migraines and nausea.
64. But by far the most problematic thing I have found is WATER, I can't drink from the tap, filtered, boiled and most bottled waters. So far 2 companies I have been buying water from have either stopped bottling or more recently Willow Water went into receivership.
65. After trying 8 different types of water from the supermarket but mainly amazon I have found Kirkland water has absolute no side effects but it does mean that I have had to buy spring water since I was in my 20's.

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66. The trigger for my migraines is usually food and drink and the doctor always prescribes migraine relief tablets which I rely on and simply cannot live without.
67. A further impact is that EVERYTHING I put on my skin, even the washing powder that I use for my clothes has to be completely plain with no perfume. I only use aqueous cream on my body and face. I can't use any type of deodorant, and believe me I have tried everything, and now given up. Hot weather is also difficult as I have to keep washing myself and my clothes.
68. Even though I am now clear of hepatitis C I am still tired most of the time and have trouble sleeping as my back pain disturbs me throughout the night. My mother is next door to me in an annexe and GRO-B so I am always running around helping her and feeling very tired, as I am her main carer.
69. Immediately 2 weeks after I completed the hepatitis C treatment I went into full blown menopause at the age of 49. Dr Pugh, the liver specialist, had told me previously that it could happen as a result of the treatment.
70. Once I started the menopause I was like a green monster and I fell out with a lot of my friends as a result. On a scale of 1-10 it was definitely a 10 as I was so snappy with everyone and not myself at all. Some relationships have since been mended but some have not.
71. After about a year of trying different oral HRT tablets, my doctor suggested trying Hormone Replacement Therapy patches that I place on my skin as I still cannot tolerate most tablets, I cannot even take vitamins. The only drug I can take without feeling sick is gabapentin.

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72. On 19 March 2013 I had my gallbladder removed and the doctors believed it was due to hepatitis C in my liver at the time. I have been cleared of hepatitis C now so the treatment worked.

Impact on Family members:

73. My sister lived 6 miles or so away and would travel down to my house to help me with things during my treatment for hepatitis C. I know coming down to see me regularly did take up a lot of her time and was not easy for her so there was an effect on her also.
74. I did not tell my other sister who now lives in New Zealand about being infected with hepatitis C as we are not on speaking terms. I believe my mother may have mentioned it to her and she most likely told one of my friend's here in the UK. I was once asked about it from a friend of mine and it was so embarrassing.

Financial Impact

75. I was running a business letting out rooms in GRO-B which entailed arranging paperwork and dealing with the tenants but I had to slow down due to treatment for hepatitis C. This led to the rooms being empty a lot of the time as I just couldn't manage all the rooms singlehandedly so they went downhill. I did approximately one viewing per day so a lot of income was lost at that time.
76. I still run the business today and I manage up to 6 rooms now but that is because I push myself do so. I do all the cleaning and maintenance and keep an eye on what the tenants are up to, make sure the communal area and the carpets are clean.
77. I like to keep the place nice for professionals. But back then I did not have the energy to do so at all. And as I have already mentioned the

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cost of the spring water that I have had to buy over the years, I could not put a figure on but I know it would run into thousands.

Section 6. Treatment/Care/Support

78. I was referred to Musgrove Park Hospital on 8 August 2007 and I was referred to a liver specialist who dealt with my care. He told me I had an 80% chance of survival but they took some time before they decided I was a 'good candidate for treatment' and luckily I did not wait very long to have the treatment.
79. I remember the consultant saying he needed to be sure I was not going to do anything 'risky' before putting me forward for treatment as the cost of the treatment on the NHS was around £35,000. I was so angry as I wasn't infected through my own fault but I was treated the same as someone who lived a 'risky' lifestyle.
80. They scanned my liver just to make sure it wasn't too enlarged so they had to gauge it. They asked direct questions about my lifestyle like whether I drank alcohol, did I take drugs, or engage in anal sex with multiple partners. It was so weird for me being asked all those questions as the answers was always no.
81. I don't remember if counselling was offered to me at the time of my diagnosis.
82. They did not show me how to self-inject my medication they just told me to jab the needle into my abdomen which my husband would usually assist me with as I did not have the nerve to do it to myself.

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83. For a year onwards I had to self-inject with interferon (Pegasys) 180mcg per week for 48 weeks, with the help of my husband and take about six tablets a day of ribavirin (Copegus) 1000mg per day for 48 weeks.
84. I did not have any difficulties accessing treatment mostly and my liver specialist, Dr Pugh gave me all the information I needed.
85. I would like to get my back sorted out but timing is a factor as it will render me inactive for a long period of time. In 2009 my GP told me to refrain from exercising which I did for some years but because of the constant pain he referred me to a back pain clinic.
86. Initially I had series of scans and MRI's and I was diagnosed with a disc dehydration at the level L5/S1. I have since had 3 injections of nerve root block but I only ever enjoyed temporary relief after each one. I was however told to resume Pilates and yoga but no high impact exercise by Dr Yee Ling Leung, Consultant Orthopaedic Surgeon.
87. Whenever I would see other medical professionals for other things I would make them aware of my hepatitis C status as I did not want to infect other people so I always made it clear.

Stigma

88. The most shocking treatment I received was when I had my gall bladder removed in 2013. The nurses put this red tape across me on the bed with a big warning sign on it, similar to what the police would use to cordon off an incident. I felt everyone, patients and staff looking at me.
89. Other patients asked me why they had done this and I had to lie and say I did not know. What was more upsetting about that was that I

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was clear of hepatitis C at that stage and the doctors and nurses knew this but they still treated me that way. I was so embarrassed.

90. At the moment my liver is well and the doctors are not doing any further tests.

Section 7. Financial Assistance

91. I was advised by Pardoes Solicitors in Somerset to apply for a government scheme called the Skipton Fund which was set up to provide financial assistance for those who had been infected with contaminated blood.
92. I completed all the forms for Skipton and I asked Dr Pugh, my liver specialist doctor to give them all the evidence. They gave me £20,000 as a lump sum payment and thereafter another payment of £4,000 a year which they divided by 12 and pay me each month.
93. I also get payments towards the electric bill for the house which I believe to be in the region of £500.00. They informed me that the monthly payments will be reviewed in line with this ongoing Inquiry.
94. It was a simple procedure to fill out the forms and I understood everything that was asked. It is harder now with the new system as there is a lot to remember.

Section 8. Other Issues

95. Only that I have had this hanging over my head for so many years unhappily and I will die unhappy.

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96. I just hope my children have a better life than I have that's my only wish. I have always felt that I've been poisoned either by the actual virus or the treatment.

Statement of Truth

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

Signed _____

GRO-B

Dated

18/4/19