

# ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0074001

Exhibits: **WITN0074002 - 014**

Dated: 13 February 2019

## INFECTED BLOOD INQUIRY

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WRITTEN STATEMENT OF GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29th November 2018.

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

### **Section 1. Introduction**

1. My name is name is GRO-B. My date of birth is GRO-B 1958 and my address is known to the Inquiry. I am retired. I intend to speak about my experience being given blood contaminated with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

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## Section 2. How Infected

2. In 1990 I had a spinal fusion at Newcastle General Hospital. I was treated by a neurologist and an orthopaedic surgeon. During the operation I was given a blood transfusion. The next day, my sister visited me in hospital. She was very distressed that there was a blood transfusion bag up. That was the first time I knew that I'd had a transfusion; I didn't have a clue before then. I was not told prior to the operation that I might need a transfusion. I was in hospital for about a month. After a few weeks I recovered from the transfusion, but it was six months before I was able to walk unaided.
  
3. I did not know that anything was wrong until June 1996, when a letter from the Blood Transfusion Service dropped on my doorstep. It said 'I'm writing with agreement of your GP regarding the blood transfusion you had in 1990. We have discovered that your blood may have been carrying infection. We have made you an appointment in July.' The bottom of the letter was highlighted, emphasising that there was no relationship between hepatitis C and HIV/AIDS. The first thing you look at is what's highlighted. It started to make me wonder what I'd got. It wasn't the greatest letter to arrive. This letter has been copied by the Investigators and is exhibited as **WITN0074002**.
  
4. The letter was a bit of a shock. It was made worse because it wasn't a great time in my life, anyway. I was quite ill and I didn't know why. I was working a lot at the time and wasn't feeling well. I had been drinking and I think I put it down to being run down and emotional stress.

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5. After I got the letter they arranged a meeting at the National Blood Transfusion Service. The doctor said that I had to have some blood tests done and she thought that I might have contracted hepatitis C through the blood transfusion. That was about it really. She said she would put me in touch with Dr Bassendine at the Freeman Hospital in Newcastle.
6. I felt confused after the meeting; I didn't know what it meant. I was told to always carry a card to let people know I've got contaminated blood. It was not until I went to see Dr Bassendine, the specialist at the Freeman Hospital, that I got some information. She did blood tests and gave me a booklet explaining all about hepatitis C, two pages of which are exhibited as **WITN0074003 & WITN0074004**.
7. That was all the information I received about it and was how I learnt about the disease. The booklet was very basic. The tests were the first ones I had for hepatitis. The doctor said I had to be very careful as I could pass it on to people but gave me, little more information. I then had further tests and scans. I was seen again in February 1997 where a liver biopsy was arranged for March. The biopsy showed mild chronic hepatitis (this was how it was always related to me). I was told that I was Geo type 1B. I have no idea what that means.
8. In 2000, my solicitor, Kidd and Spoor Legal Practice, recommended that I join a Steering Group, Deas Mallen Souter, who were going to court with lots of others for hepatitis litigation. I gave the Steering Group consent to access my medical files and they found out details about the transfusion. The blood came from unit 252924 and I was given two units.

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9. The Group asked me to see Professor Day at the Freeman Hospital to get a separate medical report. Professor Day stated in the report that he had obtained the records from Newcastle General Hospital, went through the details of the operation and that he couldn't understand why I was given blood. In his opinion, he said I didn't need a transfusion because there was no blood loss.
  
10. Professor Day also looked into my medical records to check if I had ever had a transfusion before. I had an emergency cesarean section in 1976, there were no records from this but Professor Day said it was unlikely the contaminated blood came from there. If it wasn't for the Steering Group, I wouldn't have had a clue about the fact that I didn't need the blood and how others have been affected. I was sent lots of information about the litigation and the disease.
  
11. I was later told by my GP that "I was lucky because I got hepatitis when I was young and because I was female". He said "I won't be as sick as an older person" and that I was "going to be fine".

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

12. I have not received any other infection as a result of the contaminated blood.

### **Section 4. Consent**

13. I never had a conversation with anyone before the transfusion. The only thing the doctor made me aware of, is the risks of doing the surgery and that there was a fifty percent chance I could be paralysed. Due to the circumstances they decided the operation was my best opportunity. I was told nothing about having a transfusion.

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## Section 5. Impact

14. In 1996 I lost a lot of weight quickly and was ill. I thought that this was to do with my personal circumstances at the time, but the doctor said that it was probably linked to the hepatitis infection. I generally felt run down, had a lack of energy, very itchy skin, yellowing of my eyes and skin and lots of acid build up. My body just didn't feel right and I wasn't sure why.
  
15. At first, I didn't understand the problems of alcohol, I was only told that I shouldn't drink excessively. In 1999, before the treatment, I was drinking. When I was on the treatment programme I was very ill. It was like someone had instantly given me the flu. The symptoms were shaking, stomach cramps and nausea. I didn't know why. As soon as I stopped drinking, the symptoms stopped. My GP told me it was due to hepatitis flaring up. I was also supposed to have a salt-free diet, which I wasn't informed of until I was laying in a hospital bed after another liver biopsy.
  
16. There are now medications for my arthritis which I can't have because of my liver problems. I have missed out on some medications which could have been better for me.
  
17. I didn't think the hepatitis had bothered me mentally, but it did. The worst thing was having to tell my new partner and explain it to him. It had a knock on effect because at the time, I wouldn't marry him. I didn't want to be a burden and I probably assumed that at some stage I'm going to get ill and I didn't want him to have to look after me. It sounds silly, but it was in the forefront of my mind.

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18. After I received the initial letter I felt depressed. I had a fourteen year old son at home. He saw the letter and went to school, asking his teacher whether I was going to die. I remember it like it was yesterday. It hit me, trying to reassure him, saying "don't be daft, I'll be fine." I hadn't thought about it until then. His teacher said that if I was looked after I would probably be ok, but that people did die from it. It was a bit of a shock. I don't think my son has ever asked me about it again. I don't think he wants to think about it.
19. I was estranged from my family at the time so I didn't have a support network. Nowadays, my family and my close friends know. My husband's family keep asking what's wrong with me and I just say it's my arthritis.
20. The next thing that came along was being moved off a job I liked because I might infect somebody. I was working for Marks and Spencer in the food department and they were opening a new bakery side. I asked to be transferred there. I had already asked for time off to go to Liverpool for a biopsy as I had to disclose it. I thought I was doing the right thing telling them the truth, but they said they couldn't allow me to work with food and I'd be better off working in textiles. I'd never come across anything like that before. It made me angry. It wasn't my fault; I hadn't asked for this. Why was I being held back? It had an effect. I left the company.

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21. I left Newcastle in 1998 and moved to the GRO-B regularly making trips back to see Dr Basendine. In 2000 I was transferred to Dr Smart, Dr Gilmore and Professor Lombard at the Royal Liverpool Hospital. Dr Bassendine had written to my GP in the GRO-B to see if I could be seen by someone in Manchester. The Government wouldn't fund anything for me to go there, so I had to go to Liverpool Royal Infirmary. They saw me on a regular basis.
22. It was decided, after another liver biopsy, that I started to show scarring and fibrosis. Although this was mild, it was acute enough for them to offer me treatment. I thought that this was going to make everything go away, I would be fine and not have to worry. I went and had the treatment and that made me depressed and nearly suicidal in a very short period of time.
23. In August 2000, I was treated with Ribavirin, taking 1000mg in the morning and 3,200mg in the evening, with Interferon injections three times a week. I had started a new job and I had to leave within two weeks of starting treatment. I was offered the treatment for six months; I lasted eleven weeks. I was in a wheelchair at the end of that because I couldn't walk. The nurse said there were 48 potential side effects and I had 46 of them. The treatment affected my blood count and I lost the use of my legs. I had nausea, an upset stomach, headaches, constant back ache, lack of sleep, hair loss, blurred vision and confusion. I nearly set my sister's house on fire because I left a pan on the stove, it caught fire and I was just sat there, oblivious. I was feeling down right awful.
24. I was also abusive to my husband. Every time he had to give me the injection, I blamed him because it made me so sick. It had a terrible effect on him for weeks. Our relationship was tested while I was on the treatment.

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25. It took me three months to recover from the treatment. The clinic where I live didn't know how to treat me or about the drugs which Liverpool were giving me. There was no medical person to keep an eye on me; it went on longer than it should have. I was later told that the effect of the treatment was probably the cause of my borderline glaucoma and early cataracts.
26. I did have trouble getting funding for treatment. I wanted to be under the doctors in Manchester but the [GRO-B] wouldnt fund it, so I was told I had to go to Liverpool.
27. In 2001 I stopped going to Liverpool and was seen on the [GRO-B] again because the Government are trying to tighten the reins on finances. They said that my six monthly reviews can be done [GRO-B] [GRO-B] They don't have a specialist, just a consultant gastroenterologist.
28. Three years ago I asked to be referred back to Liverpool because I had a horrendous biopsy, done on the ward, in bed. I had terrible pains and received awful treatment, with no follow up. I was worried that the doctor had punctured my lung because of the symptoms I experienced. I had a scan and an ECG to check if my heart was ok. I asked again to be transferred to Liverpool and was declined. The doctor rang me and said I was a "selfish person wasting Government money." Where I live, I can't have the special liver scan which means that you don't have to have a biopsy; the hospital doesn't have that facility. This means I will have to keep going for biopsies every four years, to keep checking on my liver. The procedure is very painful.
29. Recently, I've been told that I won't get funding for any more treatment. I still carry the infection.



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30. In the medical profession, I had to tell people about my illness. I went to the dentist and they said I can't have the appointment I wanted and that I had to come at the end of the day because they have to deep clean the clinic. That's not something nice to be told. Every time I go to the hospital they print off sheets saying 'high risk - hepatitis C.' Sometimes at the blood clinic, I have tests done and then the forms aren't filled out correctly, so I have to go back and have the tests done again. I have had a few orthopedic problems and every time I go into the hospital I have to tell them I have hepatitis C, when and how I contracted it.
31. I worked in a hardware store for some time, dealing with lots of things. I cut myself and I had to say to the boss that I needed a plaster. He said "why? It's only a scratch." Then I had to tell him and people don't leave things alone. They have to 'nit pick' and say "why?" I had to tell my employer because I needed time off to go forward and back to Liverpool. I haven't worked for a good few years now, not since I had the treatment. There's nothing worse than not being able to work, even part time. I can't commit to a job because I'm always having to have time off for hospital appointments, scans, biopsies and treatment.
32. I find travelling really hard now. It takes a lot out of me. I don't get to see my family as much as I wish I could because travelling leaves me in bed for three days when I get home.

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

33. With something like hepatitis, you tend to live with it and put it in the back of your mind. It's only recently that I've been seeing a therapist. I was never offered any support or counselling. Due to my pain control and only recently being able to talk about my medical history, it is that the hepatitis C is being spoken about. I try not to talk about it.

## **Section 7. Financial Assistance**

34. In June 2002, I got a letter from my solicitor enclosing a cheque for a secondment against the National Blood Authority, with a consent order attached. I was given £10,000 and had over £2,000 legal fees to pay, despite receiving legal aid. (Exhibit **WITN0074005**)

35. In September 2004, my solicitor advised me of a Department of Health ex gratia payment scheme for individuals. I was told that anyone who had successfully obtained damages from the litigation can claim for a payment under the Skipton Fund. I rang the helpline and was told that I should be entitled to £20,000, which I received. I was also told about an additional £25,000 if I went on to develop more serious diseases. I was aware there were other funds but I never asked about them. After the lump sum, I received a monthly payment of £203.

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36. I currently receive a monthly payment from EIBSS. I got in touch with them four years ago as I had heard something about hardship funds to help with finances. I spoke to someone on the phone and they asked me if I needed financial help and could provide numbers for help with finances, debts and other things like that. At the time I was very poorly, so I asked for help with respite care. They said yes and the doctor sent a letter stating it would benefit me to have a holiday. I sent the receipts to them and they sent me £1,500. It was a great help. I also get the winter fuel allowance from them.
37. When my husband was working (self-employed), we were having financial problems and they said I can apply to the Caxton Foundation. They wrote to me at the time saying there were five funds combined into one and it was means tested. I had to send my husband's tax forms in order to prove his earnings. They gave us an allowance of £202. Then they stopped it because my husband started earning more one year.
38. I currently receive £433 a month from EIBSS.
39. I think it's horrendous trying to apply for anything. The paperwork is beyond me at times and I did apply for help with it. It said somewhere that I had to prove my eyesight was down to the hepatitis. I can't prove that I have bad enough eyes and my optician thinks it's down to the medication I've taken. I also have issues with the dentist saying my problems are down to hepatitis, but they can't prove that. I filled out the paperwork and got all the receipts and they still wanted more. I was so tired that I couldn't be bothered and I forgot about it. It was very difficult. I get that there isn't a never-ending pot of money. People worse off than me shouldn't have to put up with that and shouldn't have to go through reams of paperwork and stress to prove that they have the illness.

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40. There were no pre-conditions on any of the grants. I was just informed that I could claim more if I get ill. I remember reading a document that I got saying that they anticipated someone would get £1,500 for every liver biopsy they had undertaken; the Judge thought that was too much and gave people a one-off payment of £500. I thought it was ridiculous considering what people have to go through.

41. When I found out about the Funds, it was great. Financially it helped us, because I couldn't work. Getting the money was a great bonus.

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

42. I have given the investigator a number of exhibits. Exhibit 002 is a letter from the National Blood Service informing me that I may have hepatitis C. Exhibits 003 and 004 are from the Patient Information Booklet on hepatitis C which was given to me by Dr Bassendine. Exhibits 005-008 is the letter I received from my solicitor informing of a settlement in the litigation against the National Blood Authority. Exhibits 009-014 are extracts of a diary I kept while receiving treatment and the side effects I experienced.

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Exhibit number	Description	Page number
WITN0074002	Letter dated 23 July 1996 from National Blood Service informing may have HCV	1 of 1
WITN0074003	Front page of 'Patient Information Booklet' given to [GRO-B] re hepatitis C	1 of 2
WITN0074004	Contents page of same booklet	2 of 2
WITN0074005	Cover letter from [GRO-B]'s solicitors Kid and Spoor re settlement from National Blood Authority – dated 25 June 2002	1 of 4
WITN0074006	Letter from [GRO-B]'s solicitors Kid and Spoor re settlement from National Blood Authority Titled 'Your Case' – dated 8 March 2002 (Page 1)	2 of 4
WITN0074007	Page 2 of above	3 of 4
WITN0074008	Page 3 of above	4 of 4
WITN0074009	[GRO-B] diary re 'Treatment Record' – '21.8.2000 Day 1 – Monday'	1 of 6
WITN0074010	[GRO-B] diary re 'Treatment Record' – 'Wednesday 23rd August'	2 of 6
WITN0074011	[GRO-B] diary re 'Treatment Record' – Friday 25 <sup>th</sup> August'	3 of 6
WITN0074012	[GRO-B] diary re 'Treatment Record' – 'Saturday' (believed 26.1.00)	4 of 6
WITN0074013	[GRO-B] diary re 'Treatment Record' – 'Monday August' (believed 28.1.00)	5 of 6
WITN0074014	[GRO-B] diary re 'Treatment Record' – 'Thursday 31 August'	6 of 6

## **Statement of Truth**

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

Signed

[GRO-B]

Dated 27 /2/2019