

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN0398001

Dated: 7 March 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request made under Rule 9 of the Inquiry Rules 2006 dated 03 January 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1938 and my address is GRO-B Bristol, GRO-B. I am a retired Auxiliary Nurse and now live alone. I am 80 years old and am a widow. I have made this statement with the assistance of my daughter in law, GRO-B. She remembers dates far better than I do.
2. I moved to England from Jamaica with my husband when I was 20/21 years old. I intend to speak about my infection of Hepatitis C from a blood transfusion. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on me. I have been told that as a result of the new treatment I underwent, I am now clear or at least in remission of the Hepatitis C virus.

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3. Before leaving Jamaica my husband and I had two sons. We moved to England in about 1960, I cannot be exact regarding the dates. Sadly, both of my sons have now since died. My eldest, GRO-B died from bowel cancer when he was 57 years old. My youngest, GRO-B was 56 years old when he died from heart problems.
4. I have six grandchildren, three from each son. My husband died of stomach and testicular cancer in the late 1990s. He was a taxi driver and moved to England first and I joined him shortly after. We never knew I had Hepatitis C before he died.
5. I have been on my own a long time but my sons looked after me while they were alive and now my daughter-in-law, GRO-B looks after me. We are very close. For family and personal reasons I wish for my identity to remain anonymous.

Section 2. How Infected

6. As I just mentioned I had my two sons in Jamaica before I moved to England. After I had given birth to my youngest I started experiencing some health complications relating to my womb, I had fibroids.
7. I had a lot of heavy bleeding especially around my monthly cycle but it seemed to be continuous, the bleeding would ease up just as the new cycle would start and then the bleeding would start again.
8. As I was still quite young at the time the doctors tried lots of measures to resolve the problem, they were very reluctant to take any drastic measures. Because of my age they thought I could still have more children.
9. They tried everything they could to prevent the need for a hysterectomy but nothing could be done; the fibroids just kept getting worse and worse.

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10. Sometime in 1981, April or May, I was taken into hospital as an emergency admission. GRO-B actually called 999 and requested an ambulance because I was bleeding so badly. They had to perform an emergency hysterectomy operation at the GRO-B in GRO-B. The hospital no longer exists. I was about 42 years old at the time.
11. I had lost a lot of blood and I had blood transfusions during the course of my hysterectomy. I know this because I saw the drip in my arm after I came round from the anaesthetic. I was in hospital for at least two weeks; I convalesced in a home for at least four weeks. After this I recovered at home. I was off work for at least six months.
12. Not long after, sometime in the February 1982, I started feeling unusually tired and very lazy in my body. I actually fell in the snow that winter and damaged my back.
13. I know that at some point after that operation I felt so different, not like the person I had been before. I felt so bad that it changed me completely. I felt very unwell and couldn't understand why?
14. I kept going to my GP surgery, GRO-B Surgery for tests. Although I saw a different doctor every time and I had to keep going back and forth. They kept testing me and sending me to get more blood tests but I was never told what was wrong with me. No one told me what was wrong with me until several years later when I became very, very ill.
15. I can't explain the feeling but it was awful, it is a horrible thing to be so unwell all the time.
16. I had to stop working because of how ill I felt. I had no energy and I was so tired all the time.

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17. I went for so many tests and to so many appointments at my surgery and was never told anything and I know for sure that they were hiding my illness from me.
18. I realise that they must have known from early on but they didn't want to tell me. I don't know why they didn't tell me because with the amount of blood tests I had had they must have known.
19. I remember I went to one appointment and saw one particular doctor and she looked at the results of my blood tests and said, "Why did this have to happen to you". I asked her what was wrong but she wouldn't tell me. I cannot remember the doctor's name nor how many years ago this was. It was quite a long while ago.
20. I kept going back to see them because I felt so unwell and no one ever told me anything. My view is that I think they didn't want to expose what was going on. I think they thought I was going to die and because of that they didn't want to tell me.
21. Finally I went back to my GP surgery and saw a new Indian doctor, called GRO-B he said he had to find out what was going on with me, he took some of my blood and sent it away for tests.
22. He was the one to finally tell me that I had Hepatitis C, This would have been around 10 to 15 years ago. I cannot be exact. I had never met him before that appointment and I know it was the first time I had ever seen him but he was the only one to tell me what was actually going on. As well as telling me I had Hepatitis C, he also made sure the condition of my liver was assessed. I must have had the virus for over well over 25 years before I found out.
23. When I was diagnosed with the Hepatitis C virus I was given no information about precautions I should take. I don't know if this is because

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by this time my husband had died, so the medical professionals knew I was by myself?

24. I was given no advice, absolutely nothing at all. I understood that if my blood mixed with someone else's then they could have gotten my illness. They didn't give me any help regarding my interaction with my Grandchildren or explain how I should care for myself. They left me on my own to plod along, no one told me anything.

25. Eventually I was sent to have a liver biopsy and I remember that was awful, it was very painful.

26. It took so long for me to be diagnosed that although my husband was still alive when I had my hysterectomy he died before I was told I had Hepatitis C. On reflection I could have passed the virus on to him without even knowing.

Section 3. Other Infections

27. As far as I am aware I was never tested for any other diseases.

28. As far as I am aware I don't have any other viruses.

29. My blood sugar levels are tested.

30. I had to be tested for dementia because my memory was so bad. I will discuss this in further detail later in my statement.

Section 4. Consent

31. The doctors didn't ask my permission when I had the blood transfusions during my hysterectomy. They didn't in those days, they didn't tell you anything.

Section 5. Impact

32. As I have mentioned I had to stop working because of how unwell I felt. I never had any energy and I had pains in my side which I now know was because of the damage to my liver.
33. Some days all I could do was sit on my sofa in my house from morning till night with no energy just feeling so awful.
34. I used to work as an auxiliary nurse and before my diagnosis the hospital I was working at were in the process of making some changes that meant that the nurses had to move to a different hospital. I found it very difficult to keep up with the other nurses because I felt so unwell.
35. When my husband was alive he worked as a taxi driver and he used to take me to work before I learnt how to drive. It would have been hard to get to work without him. Because of the fatigue, I had difficulty walking any distance.
36. I have had to give up driving as a result of my lack of concentration. As my condition worsened so did my mobility. This I believe was down to how the Hepatitis Virus has affected me. I used to be very active and was always out and about. Having my car enabled me to retain my independence, now that I have had to give this up I feel that my independence has been taken away from me. This has had a huge impact on my life.
37. I remember in the winter I used to feel so sick and like I was going to faint. I was so tired all the time. I felt like I couldn't tell work about how unwell I felt because in those days if you didn't work you didn't get paid. I just prayed that I could get to work and have a cup of tea and some toast and then I would feel refreshed and be able to start again.

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38. It wasn't a nice experience to go through what was happening to my body. My body was not fit enough; this was through no fault of my own. I have always eaten healthily and I don't drink alcohol.

39. I was only in my late 50s or very early 60s when I had to stop working. Because of the Hepatitis C, I was no longer capable; I just couldn't manage the day-to-day demands of a busy nurse.

40. My body was tormenting me. I have never been a lazy person but I didn't know what was wrong with me until I was diagnosed.

GRO-B

41. After I stopped nursing I went to a local college and took a course to improve my sewing skills. Sewing had always been a hobby of mine. I did this because I wanted to do something else after I had to stop nursing.

42. The sewing was easier for me than nursing because I wasn't on my feet as much or looking after patients.

43. I love sewing, I made trousers for my boys and husband when they were alive and I still make dresses for myself. After I stopped being a nurse I became a dressmaker. Being a dressmaker is the best thing I ever did and I still do it now.

44. As I mentioned earlier, before I was diagnosed with Hepatitis C, I was tested for signs of dementia. My memory was so bad that the medical professionals had to test me to determine whether or not I had dementia. When the scans of my brain came back I was told there were absolutely no signs of dementia. It was just the Hepatitis C that was affecting my memory and concentration; I just didn't know it at that point.

45. When I was finally diagnosed I was so embarrassed and shocked. I felt so shameful and I have kept it a secret from many people.

46. I told one of my young church sisters because she was a fully trained nurse and had experience as a health officer and midwife. She told me she was going to do some research about my illness and gave me information.

47. GRO-B my daughter-in-law from my youngest son knows everything. She is very close to me; she is like a daughter to me. She is my carer and she'll do anything for me. She does so much for me, like take time off work to go to the hospital with me, she calls me Mum.

48. My other daughter-in-law from my eldest son doesn't know anything. I don't think any of my grandchildren do either. I am a very private person and I find it shameful to talk about what has happened to me and the damage that has been caused to my liver. I pray to God every day. I don't want them to know because I don't want them to worry or think any differently about me.

49. I like going on holiday, especially back to Jamaica but the cost of insurance for me now means that I go without taking any insurance out. I know that if I were to disclose my illness the insurance price would be very high. It's far easier for me to take the risk and not have any instead of lying on the forms.

Section 6. Treatment/Care/Support

50. I remember being seen by a consultant at Bristol Royal Infirmary Hospital and she was talking to me about Hepatitis C and the treatment. She told me that her mother was a similar age to me at the time and because the treatment was not nice, she wouldn't want to see her mother go through the treatment so she recommended that I didn't get any treatment. Everyone thought I was going to be dead by 2010.

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51. In the January of 2015. I became unwell again and needed another transfusion. I was very anaemic. My treatment was at Bristol Royal Infirmary.
52. It wasn't until last year, 2018, some 37 years after I was infected that I finally had some treatment for the Hepatitis. I was told that it was a new type of treatment.
53. Before I received this treatment I had to have an operation to remove a growth, which was behind my right eye. Had I not had the operation I would have lost my sight. The downside of this operation is that I now have no sense of smell and I have lost my ability to taste food. I no longer really enjoy eating. I had to make a full recovery before the Hepatitis treatment commenced. I had to undergo several tests to ensure I was fit enough.
54. I started this course of treatment in summer of 2018 and it lasted three months. I had so many tablets that I had to take and it was so complicated to understand GRO-B had to help me with this.
55. I can't remember how many tablets I was taking a day but I know it was a lot. The treatment was very overwhelming. I had to tell the hospital how difficult it was for me to organise all the tablets.
56. The tablets made me feel unwell, however because I am not working I just braced myself and had to manage until I started to feel more like myself.
57. The side effects of this treatment were not nice. My skin felt very itchy all over and it was absolutely awful, I sweat at night but I don't know if this was due to the tablets or not. The itchy skin was the worst side effect of the treatment. I was itchy all over my body. I also felt a little depressed and gained a lot of weight, which I wasn't happy about. I couldn't wear the lovely clothes I had made.

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58. I didn't have any pains but the tablets did make me feel very tired and sleepy. It is a hard feeling to explain.
59. I have been told that this treatment worked and I am now in remission of the Hepatitis C, however I still have pain in my liver.
60. I feel like I'm not sure if I am clear of Hepatitis C or not, I have been told that I am but after the lack of honesty before I don't know if I believe it.
61. I try and look after myself but I have now developed liver spots on my body and it worries me.
62. I have to go back to Bristol Royal Infirmary every six months so they can monitor my liver. At my age I find this a nuisance.
63. I have been told I have cirrhosis of the liver and the hospital was very blunt in telling me that if I get cancer of the liver I will die. As far as I am aware the doctors haven't hidden anything from me this time.
64. I have to go to the hospital later this month to have an x-ray; I don't feel like I'm fully in the clear.
65. I still get very tired even now. Sometimes I want to go out but I can't. GRO-B helps me do my shopping and I am very lucky to have her.
66. I have to push myself to do things and go out because I know at my age if I didn't I would just slow down and shut down completely.
67. I was offered counselling but I was told I would have to pay to go to London and get it. I wasn't interested.
68. I was infected with blood and it wasn't my fault and I have found that the less I think and talk about it the better. I didn't want to have counselling to go over what had happened to me.

69. I am a very private person, only a couple of people at my church and my sons and daughter-in-law GRO-B knew.

70. It feels shameful and disgusting even though it's not my fault. I don't want people to know about it.

Section 7. Financial Assistance

71. I received £20,000 from the Skipton Fund. They acknowledged that because I have never smoked or drank and don't have any piercings or tattoos that I contracted the Hepatitis C via an infected blood transfusion, not through any fault of my own.

72. I cannot remember exactly what happened regarding the Skipton application. I think my consultant at Bristol Royal Infirmary had to fill out some of the forms, GRO-B also helped me, there were a lot of pages. The consultant is not at the hospital anymore. She was very good.

73. I get a monthly payment from the Skipton Fund now and it goes straight into my bank account.

74. As a result of the Hepatitis C Infection I had to give up my nursing work early, which meant my own source of income stopped. I did get some money through my sewing, I also had my husband's income while he was alive but now I get his pension. When you don't have any stable or regular income and have bills to pay it is very difficult and I struggled to make ends meet.

75. The monthly payments from the Skipton Fund are a great help. I don't want to be ungrateful but I would rather have a healthy liver and my full health rather than the money.

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76. I have to keep the heating on all the time in winter because I can't take the cold at all. That is very expensive.

Section 8. Other Issues

77. If I hadn't been infected with Hepatitis C I would be living in Jamaica. I have so many relatives out there, much more than I do in this country and I could live with them.

78. I have to stay in this country because of my liver and the health care I require which I wouldn't be able to get out there.

79. I don't know if my liver is alright or not, sometimes I wonder if I'm just being told I am clear of Hepatitis C and my liver is alright. I don't know if I believe what I'm being told.

80. I find it difficult to trust medical professions because they knew for so long what was wrong with me but didn't tell me.

Statement of Truth

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

Signed GRO-B

Dated 7 March 2019