

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0430001

Exhibits: Nil

Dated: 5 February 2019

INFECTED BLOOD INQUIRY

26 FEB 2019

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B and my date of the birth is GRO-B 1950. My address is known to the Inquiry. I am a married housewife with two children.
2. I intend to speak about my infection with the Hepatitis C virus (HCV), which I contracted from a blood transfusion. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life.
3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with drafting my statement.
4. I do not understand the English language properly, so my eldest son GRO-B GRO-B interpreted during the interview.

Section 2. How Infected

5. After giving birth to my youngest son in 1979 I lost too much blood. I was given a blood transfusion two weeks after at [GRO-B] Hospital.
6. No possible risks of infection were communicated to me prior to the transfusion. I was given a paper to sign explaining that I required an operation, but I could not speak or understand the English language. My husband was at home with our son, so a female doctor got an Urdu-speaking patient to translate the letter. The patient explained that it would be dangerous if I did not have the operation.
7. Following the transfusion I became very unwell, and my health deteriorated. I experienced stomach pain, vomiting, tiredness, fatigue and was cold.
8. X-rays and tests were carried out by the hospital, but nothing was discovered. I constantly went to the GP for check-ups and was given painkillers and antibiotics to ease the symptoms. Blood tests were carried out in this period but I was not tested specifically for HCV.
9. By 2005 my condition had deteriorated considerably, so my GP at The [GRO-B] Medical Centre carried out an extensive blood test. He did not mention that I would be tested for HCV.
10. I was called back in for an appointment where the results of the blood test were discussed. I tested positive for HCV and was asked whether I had any operations in the past. Dr [GRO-B] explained what HCV was and that I would need a course of treatment to clear the virus. He did mention about the risk of infecting others but I cannot recall exactly what was said.
11. A referral was later made to [GRO-B] Hospital but I cannot remember exactly when. During the initial appointment it was confirmed that I contracted the HCV through the blood transfusion and provided with an information booklet. I was informed of the treatments available, that it

would be very hard and would have an effect on the entire body. This explanation scared me, and I was reluctant to start the treatment.

12. On 21 April 2005, I received a letter in the post from Dr Sen at GRO-B Hospital confirming that I was infected with HCV (A70z0).

13. After a few years Dr Sen convinced me to start the treatment. This was in 2011 and from this point he directed by medical care.

Section 3. Other Infections

14. I have not received any infection other than HCV as a result of being given infected blood.

Section 4. Consent

15. I was aware a full blood test was being carried out when the HCV was discovered.
16. I consented to all the treatment given to clear the virus.

Section 5. Impact

17. The main physical effect of being infected with HCV was tiredness and fatigue. I had difficulty lifting shopping, bending down and carrying out daily chores and housework became hard. I also had difficulty breathing.
18. I struggled socially due to the tiredness and was not often in the mood to be talkative.
19. Mentally I was very fearful and worried about what would happen to my health. I kept calling out to God and would pray often.

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20. After the diagnosis I recall being very upset and worried, but I was not aware of the full implications of the virus.
21. A biopsy was taken in 2011 at GRO-B Hospital to determine if there was any liver damage. The first attempt did not work, so the specialist tried again. When the needle was put in the second time I heard a snapping sound and felt pain immediately. The biopsy confirmed there was liver damage as a result of being given contaminated blood.
22. Shortly after the biopsy I was put onto a 6-month course of treatment, consisting of a weekly injection and two tablets to be taken daily. A nurse taught my husband how to administer the injections.
23. I faced no difficulty in accessing the treatment from the hospital, but did delay starting it because I was scared of the side effects.
24. During the treatment I suffered with cramps in my stomach, legs and hands and my hair became knotted. I was always tired and felt cold.
25. I remember being frustrated and worried whilst taking the medication.
26. I found it difficult to do work around the house, especially mopping the floors. Eventually I had to have a cleaner to help me, and I would order food from a takeaway instead of preparing meals. It became difficult to cook for the family because I was so tired, but I tried to do what I could.
27. I have not experienced being treated differently as a result of being infected with HCV.
28. I am not aware if my dentist was informed of my HCV status.
29. No one apart from my immediate family knows about the infection because it is such a taboo subject.

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30. I have always been a housewife, so the infection had no effect on my working life. I would have liked to participate in English classes to learn the language properly, but I was unable to because of tiredness.
31. There have been no financial effects as a result of my infection with HCV.
32. I now have check-ups and blood tests at GRO-B Hospital to monitor my condition. I used to be seen twice a year but since 2016 it has been reduced to once a year. I do not think this is satisfactory. I still have liver problems but it seems as though the doctors do not care.
33. I am unsure how far my liver damage has advanced. The hospital sends liver reports to the GP but he does not really explain what they show. He states that there will always be damage and other than that I am fine.
34. I often feel that now I do not have my health, my life is damaged.
35. My husband has always been very supportive, although he was worried after the diagnosis and throughout my treatment.
36. When I was diagnosed with HCV I decided not to tell my children because I did not want to worry them. They found out after the treatment finished and were very upset.
37. Both my husband and children have been tested for HCV but thankfully had negative results.

Section 6. Treatment/Care/Support

38. I have received no counselling in consequence of being infected with HCV.

Section 7. Financial Assistance

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39. In 2012, I was granted a lump sum of £20,000 from the Skipton Fund because I contracted HCV as a result of a blood transfusion.
40. A nurse at GRO-B Hospital mentioned the financial assistance. I was provided with a telephone number for the Skipton Fund, and received an application form after contacting them.
41. Dr Sen assisted with the application and overall it took between 2-3 months to receive the payment.
42. As part of the application I was asked to provide copies of bank statements and utility bills, along with doctors notes. I had to provide the date of my blood transfusion.
43. At a later stage I applied for a further £50,000 from the Skipton Fund, but the application form was sent back two times. On these two occasions they said it had not been completed properly. I tried to apply for a third time and went to Dr Sen but he said that he had written all he could, and was not interested in assisting further. He explained that I was not ill enough to be entitled to the payment, and I was unable to send the form back without the assistance of a doctor.
44. I also received monthly payments from The Caxton Foundation amounting to around £2000-3000 per annum during 2016 and 2017.
45. The Skipton Fund passed my information onto The Caxton Foundation, and I then applied. My doctor assisted with the form, and overall it was a short application process.
46. The Caxton Foundation has also approved grant applications for repairs carried out in our home, including the installation of a double glazed front door and new washroom. A one-off payment of £4000 was granted for the washroom.

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47. No grant application have been refused, they just ask for a builders estimate for the work before an application can be made. They have always made it clear that each application is reviewed as they only have a certain amount of money to distribute.
48. No conditions were imposed on any of the payments.
49. I now receive a monthly payment of £333.23 from the EIBSS. The Caxton Foundation passed on my details to the new scheme.
50. I do not receive any other payments.
51. I feel that the payments I have received are not sufficient. There is still work to be done in the home that should be paid for. Our house is very old and has a lot of stairs. I feel that we need a new house that is more accommodating to my needs.

Section 8. Other Issues

52. I have no other issues to raise.

Statement of Truth

As I cannot understand the English language properly (but I can sign), I confirm that, my son, GRO-B has read and translated this witness statement to me. I believe that the facts stated in this witness statement are true.

Signed

GRO-B

Dated

24/02/2019

Statement of Truth

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As my mother, [GRO-B] cannot understand the English language properly (but she can sign), I, [GRO-B] confirm that I have read and translated this witness statement to her.

Signed [GRO-B] _____

Dated 24/02/2019