

ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN0481001
Exhibits: WITN0481002 - 3
Dated:

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 06 March 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B 1958 and my address is known to the Inquiry. I am a retired nurse and have been married to my husband, GRO-B, for forty years. I am a mother of two grown up daughters and a grandmother to one granddaughter already, with another grandchild on the way.
2. I intend to speak about my infection with Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my family.

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Section 2. How Infected

3. I had mild haemorrhages early in my life, but I was just told that I was a "bleeder". I now know that I am a carrier of Haemophilia B however, unlike some carriers who are symptomless, I also suffer from clinical bleeding. I think that it is often not recognised that carriers of Haemophilia B can also suffer from clinical bleeding. I now carry a Special Medical Card with me in case I require medical care (**WITN0481002 - 3**).
4. The fact that I am a mild haemophiliac (20%) means that I have received transfusions and clotting products on numerous occasions. These were predominantly received as a result of the, at least, five major haemorrhages I have had in my life. I also receive annual check-ups at the Haemophilia Centre. I do not know which of these transfusions or blood products resulted in my infection with Hepatitis C.
5. The first transfusion I received was in 1969 when I had surgery to remove my appendix. After the surgery I received six to eight units of blood.
6. My second transfusion was in 1984 when my daughter was born. Again, I required six to eight units of blood.
7. I also received dental treatment a couple of times in the 1980s, although I do not remember the specific dates. Due to my haemophilia, I sometimes had to be admitted to hospital for dental treatment. Both of the procedures in the 1980s required hospital admission. I would receive steroid injections, bloods and blood products for my dental treatment.
8. When my second daughter was born in 1988, I received blood products to prevent any haemorrhage from occurring. This was done because of the difficulties I experienced during the birth of my first daughter. I am sure that this was cryoprecipitate.

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9. My fifth haemorrhage was in 1991 when I had my hysterectomy. Four days after the procedure, I had a haemorrhage that required a hospital admission and a blood transfusion.
10. Whenever I had surgery I would receive a clotting factor, Factor IX, at the Haemophilia Centre before the procedure. In addition, I would keep a box of Cyklokapron at home to assist with clotting. I was treated at the Haemophilia Centre which is now based at Belfast City Hospital and is the Haemophilia Centre for the whole of Northern Ireland. At the time of my treatment, the Haemophilia Centre was based in the Royal Victoria Hospital, but it moved across the city approximately fifteen years ago.
11. I received transfusions at the Royal Victoria Hospital and the Belfast City Hospital. I also have received a transfusion at the Waverley Hospital but that has closed now. I used to attend the Belfast City Hospital for my blood products and I now receive steroid injections at Musgrave Park Hospital in Belfast.
12. I found out that I had Hepatitis C during my annual review at the Haemophilia Centre. I do not remember exactly when this happened but it was at some point in the mid-1990s. During my appointment the doctor, who would have been a Senior House Officer, asked me how I was coping with my Hepatitis C. I was totally shocked; I was sitting on the couch in the doctor's room and I remember I nearly fell off it. I think that, maybe, the doctor thought that I already been told that I had Hepatitis C.
13. Before I was told about my diagnosis, no one had ever suggested that I was at risk of having contracted Hepatitis C and nor was I aware that I had even been tested. It had never entered my head that I might have contracted an infection. I was a nurse when I found out that I had contracted Hepatitis C, but I do not believe that my testing was done because of my career.

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14. The doctor saw that I was shocked when she told me I had Hepatitis C. I do not really remember the last part of the appointment but I know that I asked to speak to a senior doctor. I briefly saw a consultant, Dr Mayne, who told me that my diagnosis was unfortunate but that I was not to worry about it. I was told that there would be a treatment on the way but that at that time it was not treatable. I feel like there was not a lot said about it at all to be honest. I was told that we could discuss it at another time and given a leaflet. I felt dismissed.
15. The leaflet that I was given outlined what hepatitis C was and the modes of transmission. I felt that the information in it was very limited. It was just a simple two-page leaflet as far as I remember. I do not remember what it said about how Hepatitis C could be transmitted.
16. I walked out of my appointment that day feeling like I had been handed a death sentence.
17. I do not know when I was infected but it was long before I was told. What I do not understand is that the hospitals knew which blood products has been given to which patients; so why didn't they know that I was infected earlier? Did they not use the batch numbers to work out who was given infected blood?
18. I find it frustrating that I do not know when I was infected. I was having annual blood tests at the time so, surely, in the best case scenario they would know the year that I was infected and in the worst case they would, at least, know the decade?

Section 3. Other Infections

19. I was sent a letter in the mid-1990s, which stated that I was at risk of suffering from CJD at some point down the line. I felt like the risk was played down. I remember thinking to myself "what next" and just sort of blanked it out. I have never heard any more about it.

Section 4. Consent

20. I know that I was tested for Hepatitis C without my consent. I know that I received an annual check-up at the Haemophilia Centre and had numerous samples of blood taken but I was never asked whether they could test me for hepatitis C. I never agreed to be tested.
21. I suspect, but I do not know, that I was tested for HIV at the same time I was tested for Hepatitis C. If I was tested then this was done without my consent. After I found out that I had Hepatitis C, I consented to a HIV test.

Section 5. Impact

22. I do not think that I had many symptoms before my diagnosis. I was tired but I think I put that down to being a young mum with a full-time job. I now wonder whether it was due to the Hepatitis C.
23. I was in quite a state for a few weeks after my diagnosis. I was trying to hold down a full time job, bring up two children and come to terms with living with a dire diagnosis and uncertain future. I thought that I would die soon and found myself full of questions; I worried what was going to happen to me and my family.
24. My diagnosis was tough on my husband and my young family. I was constantly worried about the risk of infecting them, so it affected my personal and physical relationships with my children and my husband. I was scared to touch my children; I was anxious when it came to hugging them. I would be frantic if one of the children used my toothbrush or if they touched a drinking glass that I had used.

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25. It changed our family dynamic for a long time. I tried to tell the girls in a very simple way what was going on but they were young and they did not understand. Now that they are adults my daughters know why I behaved in this way and they understand and support me; but I know it was difficult for them growing up.
26. I had brief conversations about how Hepatitis C was transmitted. I asked a doctor, either Dr Mayne or GRO-D how it could be transmitted. I was told that the only real way of passing on the infection was if you opened your vein into someone else's. Despite this I was also advised to use contraception. These conversations did not really help me, I was anxious until I cleared the virus that I would infect someone else.
27. My diagnosis made things difficult with my husband and thank goodness we had a stable relationship. Our personal relationship took second place for a long time because I had so much else to go through
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28. I think that having Hepatitis C made me a lot more insular. I think that I would have been more outgoing if I had not been infected. I share a lot of my feelings but there is a reluctance and a fear of intimacy, especially among groups of people.
29. For example, could not cope with the idea of going to a group and then meeting for tea afterwards. I am a wee bit better than I was while I was still infected but you just do not realise how much it impacts you until you look back on it.
30. I felt that there was significant stigma about Hepatitis C so I only told members of my close family. There are still members of my family who do not know to this day. Part of why I am uncomfortable telling people is that I know that their relationship with me would be very different afterwards. At times I felt like I lived a double life because I could not

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fully share who I was; no one really knew me outside of my own house. There is still a stigma but I think it used to be worse. I did not want people to think that I was a drug addict. I also did not want to be judged.

31. I never felt able to share my diagnosis with my colleagues. I told occupational health but not the other people I worked with. I knew what their perception of me would have been. It was hard when I was feeling unwell at times. I think my colleagues must have thought I had flu every couple of weeks.
32. Keeping my diagnosis private was difficult because I worked in the hospital that I would also receive treatment in. On one occasion when I went in for surgery I knew the surgeon. Fortunately, I knew him well enough to know that he was not going to share my diagnosis, but it was always hard when colleagues were reading my notes.
33. I discussed with staff at the haemophilia centre whether I would have to tell a dentist, but in the end I just avoided dental treatment until it was clear that I would not be a risk anymore. I looked after my health a lot better than I had done before my diagnosis to avoid having to see medical professionals.
34. One of the main times I have felt the stigma of having Hepatitis C was when I went to a clinic to get a shoulder injection. The nurse created a massive stink about my infection risk. Fortunately, the doctor said that if infection control rules were followed then I posed no more risk than anyone else but I felt mortified. I walked straight from the clinic to the Haemophilia Centre to report what had happened.
35. On another occasion I needed a gastroscopy. There was a hullabaloo because the doctors did not know how to decontaminate the scope afterwards. I remember that they sat in front of me and discussed the fact that they might have to use an old scope and destroy it afterward. I felt disgusted and alienated. I was anxious that tens of thousands of pounds of equipment would be destroyed just because it had been

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down my throat. I was also told that I would have to be last on the surgeon's list for the day so that I wouldn't put anyone else at risk. In some ways these issues were discussed with me, but mostly it felt like it was just discussed in front of me.

36. As a nurse myself for almost forty years I feel that the perception of Hepatitis C among health care professionals was atrocious. As a patient I was always concerned when going to see a health care professional about what their perception of me would be.
37. In some ways the fact that I was a nurse helped me but in others it made it worse. I was more vigilant about the treatments I was being offered, but I was also worried about the impact that my infection would have on my career. I told the Occupation Health department about my infection and once I had done that I was reluctant to take any job that would involve changing my NHS Trust because I would have had to explain it all over again.
38. I feel like the Hepatitis C and the treatment interfered with my further education. I studied for, and received, a certificate in Health and Social Care Management. I wanted to go on to do the diploma but it was around the time of my second treatment. I found myself putting it off and then I stopped all together. If I had received the diploma it would have helped my career.
39. My stamina and concentration were totally changed during the treatment and I know that I could not have got through it. I also know that, even now, I would not be able to get through something like an Open University degree.
40. I did not have cirrhosis as a result of the Hepatitis C, I was monitored at the Royal Victoria Liver Clinic on more than half a dozen occasions and I even had a scan done.
41. I received my first course of Interferon treatment shortly after my diagnosis. I was very tired for the entire time that I was on the Interferon.

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I was also nauseous, had aching bones, a terrible lethargy and a vagueness or forgetfulness. It was very hard, physically, to keep going. The treatment lasted for a year and I was determined to complete it because all of the suffering had to be worth it in the end.

42. My viral load initially dropped to maybe half the original level which was encouraging. During the course of the treatment I experienced a few false negatives and each of these was very disappointing. At the end of the treatment I was still positive for Hepatitis C.
43. My second round of treatment was the Pegylated Interferon treatment. I was absolutely exhausted the whole time. The injections made me perspire so I would take them in the evening but then I would lie in bed perspiring all night. I would also get up in the night regularly with a headache. During the treatment I struggled to concentrate. This was particularly bad the day after a treatment. As well as the fatigue I would also experience a lot of muscle soreness.
44. I think I had to have injections a couple of times a week. I remember that I would inject myself and then 4 or 5 hours later it would feel like this internal wall went up. I would start to feel hot and headachy.
45. During the treatment I went to the clinic and they thought that I was clinically depressed. Everything that I was going through was getting to me. I was becoming more and more paranoid. I would become anxious merely walking down the street. It was so bad that I did not want to continue the treatment. I was advised to go onto anti-depressants and was asked to take them to get me through the rest of the course of treatment, which I reluctantly did.
46. The anti-depressants did see me through the rest of the course but how I was feeling was completely debilitating at times. It would sometimes stop me leaving the house completely. I would make plans and then when it came to it I just would not have the pith to go.

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47. The second course of treatment was eighteen months long and during that period my older daughter undertook a placement in France while at university. She wanted us to visit her in France and I did not want to disappoint her. I remember I had to take my injection a day early and I had a miserable first few days. I had to travel without health insurance because I just could not get any, because of the infection.
48. The treatment caused a lot of strain because all of my days off work would be taken up at the clinic. I also had to use a lot of my annual leave. As a result I never felt like I had the chance to get any rest. I would have to travel to the clinic for the appointments but also each time I needed to collect doses of treatment. On a couple of occasions the treatment was posted to me but this was not a routine procedure.
49. A few times during the second course of treatment I had to phone in sick to work because I was not physically able to make it in. I had not disclosed my illness to all of my colleagues I could not really explain why. I never lied but I could not be specific.
50. My financial situation and the fact that I had two children to support meant that I needed to hold down a job during the treatment, but at times my extended sick leave meant that I would receive half or no pay.
51. I felt that taking time off put a financial burden on my family. At the time of my second treatment my husband had just started to do a degree in Theology which meant that I was the breadwinner. The credit card would take a banging when I was ill and we had to cut back a lot of our spending.
52. I think that since the Hepatitis C and the treatment I have been more susceptible to chest infections and flus. The treatment feels like I have been through cancer treatment and my immune system just has not been the same since. I have been left with fatigue all the time now. I had a tumour removed from my stomach four years ago and I feel like

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I would have recovered from the surgery a lot faster if I hadn't had a weakened immune system.

53. I have also had other illnesses and I do not know whether these are related to the Hepatitis C. I had five attacks of Bell's Palsy over the space of four years. The last time that I had an attack it resulted in the partial paralysis of my hand. Three fingers on my right hand are partially paralysed; sometimes they move and sometimes they do not. My understanding is that usually palsy is caused by a viral load and I think that my weakened immune system has contributed to my susceptibility.
54. I took early retirement aged fifty-nine because I felt like all the different illnesses were just building up. My general fatigue meant that I realised that I had to call it a day. I would finish my twelve hour shift and would be flat out asleep until dinner time the next day. I just did not feel like I should be that tired.
55. My state pension will not kick in until I am sixty-six and my early retirement means that I would have received a better work place pension if I could have continued to work.

Section 6. Treatment/Care/Support

56. A few weeks after my diagnosis In the 1990s I was reviewed and further tests were conducted, both in relation to the Hepatitis C and also to check whether I had contracted HIV. I also received a vaccine for Hepatitis B. I felt that the diagnosis was played down again. I was told at this appointment that there were a few people who had contracted Hepatitis C from a blood transfusion but I did not get the impression that there was any sense of urgency about the infections. I also did not receive an apology and everything felt very blasé.
57. After my diagnosis I had liver screenings every year.

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58. Sometime around 1999 or 2000, I began a course of Interferon treatment. The treatment was tough and I was ill most of the time, as outlined further in the section above on impact. Unfortunately, this first course of treatment did not work.
59. When I found out that the treatment was unsuccessful I was told that there was a new type of Interferon treatment (the Pegylated Interferon) which might work for me but it was not available in Northern Ireland. I was told that this was because of the NICE guidelines and the different regulations in Northern Ireland as opposed to the other parts of the UK.
60. I believe that it was the cost of the medication which meant that we could not receive it immediately. I feel like money was put ahead of people.
61. The treatment did not become available for 18 months but eventually I was given it. It consisted of both injections and tablets. The first type of Interferon was hard but the second one was horrendous. There was very limited support; other than the support of the clinics no other help was offered.
62. The second round of treatment was successful but the side effects were even worse than the first treatment. After I was told that I had eradicated the virus I stopped receiving any scans and did not have further contact with the liver clinic. I just attend the Haemophilia Centre yearly.
63. I do not feel like I was given an explanation of what impact having had Hepatitis C may have on my future health, I do not necessarily feel like I have been abandoned but I do feel as though I have been pushed to one side. I still feel like I have an uncertain future as I do not know what the risks are of the virus returning.
64. The Health Board in Northern Ireland has always been different to the rest of the UK and even now I feel like there are differences in the level of care.

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65. I have never received any offer of counselling or emotional support. Even when I was diagnosed with clinical depression I was not offered counselling, only medication. You had your twenty minute slot when you went to the liver clinic and that was it. Towards the end of the second treatment I was told that there was a cancer centre next to the Haemophilia Centre and the Red Cross had offered aromatherapy massages there. I had three massages but that is all I ever got.
66. I think I would have taken up an offer of counselling, although my husband and I are close that isn't the same as having an independent person to speak to.
67. The only other support I received was through the Haemophilia Society. Sometimes they would have workshops or speakers who would talk about Hepatitis C. This was how I would sometimes find out information about treatments or other issues.
68. There was one session that the Haemophilia Society would run on their family fun days where we told that everything was confidential. We were able to discuss what we were going through with other people in similar circumstances.
69. This would happen about once every eighteen months. I found that these sessions were largely full of men and a lot of them had been dual infected. It was an informal network where you could speak out or get up and walk away but I never felt comfortable talking about what I was going through.

Section 7. Financial Assistance

70. I cannot remember exactly how I received financial assistance. I know that I received a letter from the Skipton Fund in the early 2000s and I remember being asked at the Haemophilia Centre if I had heard from the Skipton Fund. I was told by the Haemophilia Centre that my details had been passed to the Skipton Fund.

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71. I do remember that I filled out a form, I wish that I had kept a copy of that form. I think that the form said that by signing I agreed not to seek any further compensation. I don't think that there was anything in it about not telling anyone what had happened.
72. I think I received about £20,000 and then, I think, I received another couple of thousand a few years later. I do not remember exactly why I received the second sum of money.
73. Approximately two years ago the Skipton Fund wrote to say that the fund was being stopped and handed over to another authority. On 8th March 2017, I received a letter to say that I would be receiving regular stage one payments.
74. I now receive £300 a month. Initially the money was to be structured as an annual payment but then it was changed to a monthly payment. I am very grateful for the money but I do not feel like it reflects the impact of the diagnosis or the long-term impact that it has had on my health.
75. I do not feel like the criteria are flexible enough to reflect the individual impact of the disease. I would like to know who decided the criteria because they do not make any sense to me.
76. I am also anxious because I feel like the financial assistance I received could impact my ability to receive state support. The monthly payments have to be paid into my current account and now look like they form part of my income.
77. I often wonder how many databases I am currently sitting on. I know that information about my diagnosis and health has been shared, at the minimum with the Skipton Fund, and I do not know who else it has been shared with.
78. Having access to discretionary payments while I was ill would have helped to smooth things over for me. It would have helped me to bring

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up my children and when I was on long-term sick it would have helped to mitigate the financial impact of that. When I returned to work after a period of sickness there would always be a lot of pressure to tighten the belt and pay off the credit card as soon as possible.

Section 8. Other Issues

79. After my diagnosis, at some point in the 1990s, I remember I was told by one of my consultants that the hospitals were changing their blood supplies. They said that some of the blood products that people were given at the Royal Victoria Hospital had come from blood supplied by prisoners and people from America. I was told that they were changing to a Parisian company.
80. I feel like there is an attitude towards carriers of haemophilia that "you're just a carrier." When I completed forms for the Haemophilia Society the options on the form would be Haemophilia A, Haemophilia B, Von Willebrand's Disease or other.
81. I would end up having to write that I was a carrier of Haemophilia B with clinical bleeding. It did not feel like it was recognised as being the same disease. I think this is a shame because a man's perspective and a woman's perspective on handling a disease is a totally different thing.
82. Although the Inquiry is ongoing I do not feel like 'the man on the street' would know what it was even about. The authorities involved are still ignorant about Haemophilia and Hepatitis C.
83. In relation to Hepatitis C there is not enough information about how to behave towards people with Hepatitis C and not enough has been done to redress the stigma.
84. I have thought about asking for my notes several times but I do not know if I would be brave enough to read some parts through.

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85. I am a victim of a blood tragedy, but I am a survivor unlike other people. I feel that I need answers as to why it happened, why it was not reported earlier and why the infected transfusions were not stopped.
86. I also want to know why some treatments were not available in Northern Ireland for some time after they were available in the rest of the UK.

Statement of Truth

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

Signed _____ GRO-B

Dated 4th April 2019.