

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2771001

Exhibit: 0

Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B I live at GRO-B
GRO-B with my two dogs. I have been working as a
GRO-B for 9 years.
2. This statement is made in relation to my late mother, GRO-B: M born
on GRO-B and who passed away on GRO-B aged 75, having
contracted Hepatitis C through a blood transfusion.
3. This witness statement has been prepared without the benefit of access to my
mother's full medical records.

Section 2. How affected

4. My mother was GRO-B and my father was GRO-B They moved to the UK in the
1950s when they were in their early 20s. My mother was always very hard-

working, because she came from a background whereby she wasn't very well off. She once told me her family used to wash all their clothes in a nearby river. My mother therefore had always worked hard physically but I always remembered her to be a very strong woman.

5. I have an older sister, [GRO-B] Following the births of my sister and I, I believe our mother had two miscarriages. Both were in the 1970s and I believe on both occasions she was treated at the [GRO-B] [GRO-B].
6. She had always suffered from very heavy periods and other gynaecological problems, such as an inability to carry male fetuses.
7. One of the miscarriages in particular really stands out in my mind. I was around 12 years old and I recall my mother being quite poorly. I am unsure if whether this was the first or second miscarriage or whether this was when she had her blood transfusion. When she came back home she was very weak and I was told to be quiet and not to disturb her. This was the longest period of leave my mother had taken from her job because she was ultimately bed-bound.
8. I am not aware as to the advice, if any, given to my mother by the medical professionals before or after the transfusion. In order to receive a pay-out from the Skipton Fund after her passing I had to read through my mother's medical records and found no mention of the procedure she had when she miscarried.
9. We found out about my mother's Hepatitis C infection in or around 1998/99. My mother and I went to a fireworks show at Alexandra Palace, where we tried to climb up a hill, but my mother could not catch her breath. We became very worried, as she had never experienced anything like this before. I took her home and made an appointment with her GP, [GRO-B] in London. In the appointment [GRO-B] could not work out what was wrong with her, so he referred her to the [GRO-B] I did not attend that hospital

appointment with her; my father went instead. My mother was taken in for tests, but the doctors could not figure out what was wrong with her. She was there for a couple of days and when I went to see her one day, she looked very down and said that the doctors found that something was wrong with her liver. The doctors suspected that she might have had liver cirrhosis, but they did not understand how she could have sustained that amount of damage considering she was not a drinker and maintained a healthy lifestyle. She was then referred to [GRO-B] at the [GRO-B] This is when it was finally discovered that she had contracted Hepatitis C.

10. Initially the doctors were unable to confirm how my mother had contracted the virus and even questioned whether my mother was a drug user. Eventually, my father remembered the transfusion and the matter was attributed to that.
11. Growing up I recall my mother always complaining about being tired and having numerous bouts of ill health. I never knew about the transfusions and it was only when her diagnosis was confirmed did my father make us aware that she had required one following her miscarriage.
12. From that point on, my mother was always cared for by the [GRO-B] first under [GRO-B] and later under a different doctor (following [GRO-B] death.)
13. Following news of the diagnosis, we were not given any advice and certainly not enough information to understand and manage her infection. The only information we were given was that she had a problem with her liver and that it was not caused by alcohol.
14. My parents never felt like they were in a position to question the doctors; this was a generation of when people viewed the doctors as if they were the Gods and if a doctor said something then it must be absolute and true.

15. I later did my own research on Hepatitis C and this is when I came across the information that it was a death sentence. It terrified me.

16. Looking back now, I realise just how much of a serious illness it was and that my mother's prognosis was not good. At the time however, we were never told about it and if we were told, then it was not made clear in simple language for us to understand the severity of it all.

17. We were also never given any advice on risks of infecting others. None of us were ever even encouraged to get tested ourselves.

Section 3. Other Infections

18. I am not aware of my mother contracting anything else from the contaminated blood transfusion.

19. Certainly, we were never informed that she was tested for anything else. I do suspect that she might have been suffering from something else as well, as she had constant headaches and nosebleeds. We were never advised as to whether they were symptoms of Hepatitis C.

Section 4. Consent

20. I am not aware of if whether my mother was treated or tested without her knowledge or for research purposes.

Section 5. Impact

21. After her diagnosis, my mother's health became progressively worse. She was constantly tired, her palms were red and itchy and she used to get very bad nose bleeds, which were quite frightening. She later developed an extended abdomen, had immense difficulty sleeping and had awful headaches.

22. Mentally, she became very depressed but was never offered any medication or counselling.
23. For the first few weeks the doctors only monitored her condition. Only when her health deteriorated further, did the doctors put her on the Interferon treatment. It had awful side-effects. She felt very ill and a few weeks into her treatment she became too ill to continue. I recall receiving a phone call from her on one occasion and her not being able to move. The doctors agreed that she had an unusually bad reaction to the treatment and so she was taken off it.
24. She did not have any other treatment after that; the doctors only monitored her liver. Some days she came back from her hospital appointments happy, other times, when her liver was doing particularly badly, she became depressed.
25. Growing up there was only the four of us in our house: my parents, my sister and I. We grew up with my mother never feeling completely well and at the time it was nothing out of the ordinary for us.
26. After I graduated from University in the 1980s, my sister and I moved to GRO-
This was around the time when my father realised that my mother was getting unusually tired. However at the time I did not pay much attention to it. I proceeded with my postgraduate studies and had my own life for a brief period of time. When I moved back from GRO-B in the 1990s my parents moved in with me and this was when I finally noticed the change in my mother; from being a physically strong lady to one who had no strength at all. I was very close to my parents as they were living with me for a very long time. My sister remained in GRO-B
27. She was already very frail when she moved in with me. In the latter stages of her life, I became her main carer.

28. My mother suffered from a stroke in or around 2002 which caused a haemorrhagic bleed; thankfully, she survived. The doctors at that time said an operation to clear the clot in her brain was too dangerous.
29. My mother's illness affected many different aspects of my life, particularly after the stroke. At the time I had a full-time job at a bank which required me to travel a lot. It was a very stressful job, but I loved it.
30. In 2006, I purchased a house in GRO-B to aid her recovery. She went there once in July 2007 with my father. She was due to fly back at a certain date, but her health deteriorated and as a result she could not control her movements and facial expressions. The airport staff did not allow her to fly back home until she had a letter from a neurologist confirming it was safe for her to fly. It was a very stressful time for my parents, but her health began to improve a week later when they were both able to fly home.
31. I met her at the airport and I could not believe how much she had changed over such a short period of time. She had lost so much weight; it had been an incredibly stressful fortnight.
32. I fought hard for the care we received from the social system, but eventually I decided to become my mother's carer while still working at the bank. As a result I did not have time for any sort of social life; all I wanted to do was go home and be with my mother.
33. I had so many sleepless nights, as my mother was in such discomfort and just would not settle.
34. In September of that year, whilst I was at work, I received a phone call from my father, as my parents were on their way to the hospital. I left work and followed them to the hospital. My mother was in and out of consciousness and kept babbling when she did wake. At first, the doctors thought that she had meningitis

so she was given a lumbar puncture, but they soon realised it wasn't meningitis. They then thought that she had dementia and treated her with the wrong drug, (Gabapentin). My mother continued in and out of consciousness and was still unable to form words. The doctors finally discovered that she was suffering from hepatic encephalopathy (decline in brain function) as a result of the severity of the damage in her liver.

35. I didn't go to work for 6 weeks during the time she was in hospital. I didn't trust the healthcare professionals so I moved to the hospital and spent the nights with her. I cleaned and washed her and because her body was so swollen I hoisted her myself. She could not have solid food, so she had to be tube-fed. Whenever I was not at the hospital, I was looking after my father who had completely fallen into pieces.
36. I went back to work in mid-October 2007. I lost a lot of weight by then because of all the worry. My mother came out of the hospital and a district nurse was to set up a percutaneous endoscopic gastrostomy (PEG) feed, as she was still not able to consume solid foods. The nurse however would often not turn up until 10/11pm so I had to learn to do it myself instead. I also showed my father how to do it just in case I wasn't there. On top of all of this, my mother was a diabetic and so I had to administer her injections for her too.
37. Between the months of October and November 2007, my mother was in and out of the hospital and constantly in and out of consciousness. My work was heavily disrupted. I was informed in early December that I was at risk of redundancy and I was put on a garden leave for 3 months. I did make it clear to my employers that I knew that they were doing this because of my caring duties. Eventually, I was made redundant in April 2008.
38. I was offered a redundancy package, which I did not want. Instead I wanted to take my employer to court, but the timing was awful because my mother's health continued to deteriorate. There was a lot of publicity around that time regarding a

high profile case of a carer being made redundant but all of it would have been too much for me to handle. On one occasion both of my parents were in the same ward at the hospital at the same time.

39. My mother passed away in GRO-B. I was her full-time carer for 6 months prior to that and she was in and out of hospital as she kept losing consciousness. I was offered respite once, about a month before she died but I did not want to leave her. As she was bedbound, I set up her bed in the front room of the house, as I had already converted the ground floor bathroom into a wet-room for her. I had even considered having a lift installed in the house but my mother became unresponsive for the final time so I took her back to the hospital. She passed away a few days later.
40. I was not with my mother when she passed away. I had left the hospital that morning, after spending the night there and wanted to take a shower and I received a call from my father informing me that my mother had passed away. He was there with her. They had been married for 53 years. When she passed away he was in pieces. My father died 2 years later.
41. After my mother's death I did not work for 2 years and was only able to get another job in April 2010.
42. I decided to care for my parents full-time after I lost my job, as I was the only person they had close to them and we could not rely on anybody else. I was very aware that the health service would not provide the same level of compassion that I could give my mother.
43. My parents did not have any sort of social life. My mother could not go out and my father had heart problems. They tried to go out on walks or short shopping trips, but my mother would get tired very quickly. None of us had an active social life. On the weekends we spent time together and tried to do things which did not exhaust her. All of our activities were tailored around her illness. I did all this

while holding down a full-time job before my employment terminated. My mother had one job for 12 years, but had to give it up in 1990s, as she was not physically able to continue. She took a voluntary redundancy.

44. My father suffered from high blood pressure and heart problems, which led to angina and a heart attack. He was not strong enough to cope with everything on his own and this was the sole reason I had to step in.

45. I am not aware of my mother being subject to any prejudicial treatment due to her Hepatitis C infection. I am sure that my father would have made me aware if any such incidents had taken place as he knew that I would have defended her.

46. We never told anybody about my mother's condition. The only people who knew were my father, sister and the medical staff. We were afraid that Hepatitis C would lead to the same stigma as HIV. My mother was very fearful of it; she kept on calling it the 'dirty disease.' She must have read somewhere about it being the disease of drug addicts.

Section 6. Treatment/Care/Support

47. I believe my mother was offered and given the only treatment that was available at the time, which was Interferon.

48. I am not aware as to any other treatment at the time which ought to have been made available to her but was not.

49. After the first course of Interferon, which she reacted particularly badly to, my mother was not given any other treatment. I believe that if there was anything else out there, she should have been offered it.

50. None of us were ever offered any counselling in order to help us to deal with my mother's condition.

Section 7. Financial Assistance

51. I believe someone at the hospital informed me about the financial assistance available, so I applied as I knew that my father would not have known how to go about doing it for himself.

52. My family received two separate payments from the Skipton Fund. I believe my father received the first payment of around £30,000 between 10 months and a year after my mother's death.

53. I then had the second payment of £25,000 in 2011 because the Health Secretary had increased the amount of money that Hepatitis C sufferers were due to receive.

54. Overall, I found the Skipton Fund to be quite good and generally did not face much difficulty in applying. My application was originally declined as we were told that my mother could have suffered liver damage as a result of drinking and Hepatitis C due to drug use. We successfully appealed the decision and received our first payment.

55. I found the application process rather stressful as I had a lot of responsibilities and the application involved a lot of form-filling. I do not believe there were any pre-conditions set in place, as my mother's death certificate stated that she died due to the effects of Hepatitis C.

Section 8. Other Issues

56. I am hoping that this Inquiry will hold the right people responsible for this massive cover-up.

ANONYMOUS

57. I want an apology from the Government for allowing this to happen in the first place. I lost my mother and my career as a direct result of this.

58. I saw my mother suffer so much throughout the process and I'm sure that if it was not for the infection my mother would still be around. Her sisters lived up to their 90s and 80s. Did my mother sacrifice her life? This thought continues to be extremely upsetting for me.

Anonymity, disclosure and redaction

59. I confirm that I wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

60. I do wish to be called to give oral evidence.

Statement of Truth

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

Signed.....

GRO-B

Dated.....

28/6/19