

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2813001

Exhibits: 0

Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

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

Section 1. Introduction

1. My name is GRO-B. I was born on GRO-B. I live at GRO-B GRO-B with my second wife.
2. I am a GRO-B
3. My late mother, GRO-B: M, was born on GRO-B. She was infected with HIV as a result of having received contaminated blood products. She died on GRO-B
4. This witness statement has been prepared without the benefit of access to my late mother's full medical records.

Section 2. How infected

5. During my first year of university studying GRO-B at GRO-B in or about early GRO-B, my mother explained to me that she had been diagnosed with

fibroids in her uterus. In order to remove the fibroids, she had to undergo a hysterectomy.

6. This surgery took place in GRO-B at the GRO-B. My mother was receiving private treatment funded by BUPA health insurance which was provided by my fathers' employers. My father was an GRO-B GRO-B at a firm then known as GRO-B. My parents had opted for private care as they were going to have to wait much longer for NHS treatment.
7. During the course of the hysterectomy, my mother received a blood transfusion. This blood transfusion is the only surgery or procedure in which my mother ever had to receive a blood product. I know this because she later told me that during her hysterectomy was the only time she had received any blood products.
8. I am not aware of my mother being provided with any information the risks of infection. There were no concerns that I was aware of at the time.
9. There were no immediate issues or symptoms after the surgery; it seemed a success at the time.
10. It was not until around the summer of GRO-B that I became aware that my mother's health was beginning to decline. At the time, my first wife and I were on holiday with my parents in France. We noticed that my mother was having great difficulty in walking up the stairs where we were staying and would be struggling to breathe by the time we reached the top. My mother could well have been having similar issues prior to this holiday but this was the first time I was aware of them. My first wife, who was a doctor, advised my mother to take herself to her GP because we were concerned about her.
11. Soon after this holiday my mother visited her GP. They did various investigations and the first thing they identified was Lupus. They believed this could possibly be the cause of my mother's health difficulties. Further tests

indicated that my mother might be suffering from Antiphospholipid Antibody Syndrom ("APLS"). My mother was not at that stage given any information as to how these illnesses were caused.

12. At the time of my mother having these tests, my wife and I had recently arrived in [GRO-B] for work; there had been an earthquake in the region where we were moving and, as an [GRO-B] and a doctor, we were planning to join the humanitarian efforts there. We discussed whether to cancel these plans but my parents insisted that we shouldn't do so; at this point my mother seemed stable and so we decided we could safely make the move.

13. My wife and I moved to [GRO-B] in early February [GRO-B] and communication with my parents became very difficult. Personal emails didn't really exist at the time and it was difficult to make telephone calls from the region we were in, the earthquake had affected power and telephone lines. We were also having to do great deal of travelling from place to place. It was difficult, therefore, to maintain close communication with my parents. We would pre-arrange times for me call home. We did this as often as possible, usually about once a week.

14. Not long into our stay in [GRO-B] during one of our pre-arranged telephone calls, only my father picked up when I called. My father broke down in tears on the phone. It was difficult to understand what he was saying as he was weeping so much. This was unusual behavior from my father as he was not one to express his emotions; the only other time I can recall him crying was when his mother had passed away. He did not tell me why he was crying but he did say my mother was in hospital and that things were very tough. I found the call very distressing as I was far away and didn't understand why my father couldn't talk about it at the time. He passed it off as a "bad week" and I believe this is because he was trying to protect me and my wife. I believe my parents didn't want to say anything that would affect our decision to stay in [GRO-B]

15. The next time I spoke to my family, a few days later, my mother was out of hospital and everything continued as normal. We were aware that my mother was in and out of hospital regularly at this stage but I assumed this was to do with the Lupus.

16. In or about late June GRO-B I received a hand-written letter from my mother. The letter explained that my mother had developed Acquired Immune Deficiency Syndrome ("AIDS") as a result of the HIV virus. She told us she had been infected with HIV through the blood transfusion she received during her hysterectomy 10 years earlier. The letter explained that this diagnosis had been the reason my father had broken down during the phone call earlier in the year.

17. My mother told me that she had visited the hospital in order for treatment for the Lupus and APLS. The treatment she was going to have was similar to dialysis, in that it involved "cleaning" the blood, and she had to have certain blood tests performed before starting treatment. It was after the results of these tests came back that my mother's doctors told her she had been infected with HIV and that it had developed into AIDS.

Section 3. Other Infections

18. I am unaware of my mother receiving any infections other than HIV as a result of her blood transfusion.

Section 4. Consent

19. I do not believe my mother was aware of the risks associated with the blood transfusion that caused her infection. I do not believe my mother would have taken the risk if she had been told that she could have been infected with HIV.

20. I therefore do not believe she was given adequate information about her treatment.

Section 5. Impact of the Infection

21. My mother's diagnosis came as complete a shock to everyone. My mother told me that her consultant was so shocked by the results that he hadn't even turned up to the original consultation with my parents as he didn't know what to say to them. I remember my father was very angry about this at the time as there was no explanation for why he hadn't come, my parents had had to wait in the consultation room for a considerable amount of time before being told that he wasn't coming. I understand that a further appointment was then arranged in which my mother was told about the results of her blood tests and that she had developed AIDS.

22. My parents had told me about the diagnosis in writing because they didn't want me to do anything sudden or impulsive when I first received the news; it was something I would have to digest and come to terms with. I know my mother put a great deal of thought into the letter, after she passed away I came across a rough copy of it which she had written before writing the final version.

23. When receiving the news of my mother's infection, the family had assumed it was a one-off accident, we had no idea about the scale on which people had been infected by contaminated blood/blood products.

24. At the time we received this letter, my wife and I were due to relocate to GRO-B
GRO-B We decided to put this on hold whilst we returned to the UK to visit my mother.

25. When we returned to the UK we decided to see my mother's consultant, GRO-B
GRO-B at GRO-B My parents were not present at this meeting. My wife was a doctor and so the consultant was happy to speak to us on a professional and personal level. We asked GRO-B what my mother's likely prognosis would be. The indication he gave was that he believed she only had about a year left to live. He also said if my mother's health did start to deteriorate, it was likely to be a gradual decline rather than

a sharp one. It was on this basis that we made the decision to return to our work in GRO-B. If I had been told my mother's health would likely deteriorate quickly, I would have stayed in England.

26. My mother experienced great difficulty with her mobility as a result of her infection. She never was a very active person but I noticed a dramatic reduction in her ability to move about; climbing stairs in particular was a struggle. Towards the end of her life, there were periods when my mother was so weak she would have to be in a wheelchair.
27. My mother put on an incredibly brave face for us. She told us she didn't want us to change our plans for her. She likely masked the difficulties she had in order to protect me and my brother. In turn, my wife and I hid our concerns from my mother as we didn't want to increase the stress she was under. It must have been very difficult for her to be going through such a terrible ordeal, with the pressure of worrying about her children and how to tell us about her diagnosis.
28. My parents didn't tell many people about my mother's diagnosis due to the stigma that was associated with HIV and AIDS. At the time people still did not understand the infection and there was a great deal of hysteria in the media about it.
29. My mother also avoided telling loved ones about her illness as she knew they would be devastated by the news. As a result, my parents decided it was best if people didn't know. Even to this day, people who were close to my mother still do not know what she died of.
30. I believe my father's business partners knew of my mother's condition. My father had to take a lot of time off in order to care for my mother and accompany her to appointments. Thankfully his partners were very understanding.

31. The antiviral medication my mother was given caused her unpleasant side effects, which led to her feeling unwell, generally exhausted, and fatigued all the time. It also stopped her from sleeping properly which added to her overall feelings of ill health.
32. On my mother's birthday, GRO-B we were unable to contact my parents. We assumed at the time that they had gone on holiday. We later discovered that, during this period, my mother had in fact been in hospital as she was struggling to control her symptoms. It was during this hospital stay that she had decided to stop taking her antiviral medication as they were having such a negative impact on her quality of life and didn't seem to be stopping her from getting unwell. I knew that my mother was struggling with the side effects from this medication and so I respected her decision.
33. My mother's sister (my aunt) and her husband were aware of my mother's diagnosis. My aunt was very shocked that her sister had decided to stop taking the antiviral medication; I think my aunt felt it was like accepting a death sentence rather than trying to fight it. I think she felt like my mum was giving up.
34. When we heard that my mother had stopped her antiviral treatment, my wife and I made the decision to return to the UK. We intended to be back in time to spend Christmas with my mother. She seemed happy about this and I found out subsequently through my father that she had been delighted that we would be returning. The plan was to return by late GRO-B.
35. I called my parents on GRO-B and managed to get through to them. However, the line was extremely poor and although I was able to hear my parents, they could not hear me, which was extremely frustrating. My mother explained that she was going to stay in a hospice for a few days to give my father some respite. I was stunned as it brought home the severity of my mother's condition. The news was all the harder to take because I couldn't respond, due to the poor connection. I couldn't sleep that night and decided with my wife that I would call my parents again at the earliest opportunity.

36. The next day I had to travel for a meeting away from where my wife and I lived at the time. Whilst I was on my way to this meeting I had to stop for petrol. Another vehicle pulled up at the petrol station, carrying my wife. She got out and told me that she had had a telephone call from my father who had been trying to contact me for hours. She told me that my mother had passed away in the early hours of the morning. My father never said too much about what happened in those final hours, I believe he was too distressed.
37. It is difficult to explain the feeling of losing a parent; I was absolutely devastated and I can remember thinking how terribly unfair it was that my mother had died. I had known she was dying but it was the fact that it all happened so quickly. My wife and I had made the decision to return to GRO-B on the basis that we would be able to return to the UK to be with my mother if her health began to deteriorate. It was hard to deal with this because I never got to spend the time with my mother that I had wanted too.
38. Shortly after my mother's death my wife was diagnosed with cancer, an illness which ultimately led to her death. I hadn't even had a year after my mother's death before I was swamped with my wife having surgery, radiotherapy and chemotherapy. This meant that I never really had time to properly grieve for my mother.
39. My mother's death had a huge effect on my father. Rather than living a full life married to my mother, he merely "functioned", much as many grieving spouses do. I know he grieved deeply and struggled with what to do with himself after she was gone. He was so used to having my mother around. They had been married since GRO-B and had spent most of their lives together.
40. My father passed away on GRO-B He had a rare genetic condition that caused his death. I am now, as a result, without either of my parents. This may not have been the case if my mother had not been infected with HIV. This fills me with deep sadness, especially when I look back and think about the manner in which my mother passed away.

Section 6. Treatment/care/support

41. I am not aware of any obstacles my mother faced in accessing treatment.

42. I know that after my mother was diagnosed with HIV she attended counselling sessions with my father and that they discussed how my parents should tell me and my brother about my mother's diagnosis during these sessions.

Section 7. Financial Assistance

43. As far as I am aware, no members of family have received any financial assistance as a result of my mother's infection.

Section 8. Conclusion

44. I hope that the Infected Blood Inquiry will lead to health care providers taking greater care in the treatment of their patients and, in particular, that greater care will be taken in assessing and informing them about the risks of any procedures.

45. It is important it is not just left at people being made aware of what has happened, or that regulations are put in place; what happened to my mother was entirely preventable and it must be prevented from ever happening again.

Anonymity

46. I wish to remain anonymous and I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-B

Dated... 8 July 2019