

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN0199001

Exhibits:

Dated: 16th MAY 2019

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 20 November 2018.

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

Section 1. Introduction

1. My name is **GRO-B**. My date of birth and address are known to the Inquiry. I am a wife and mother who works as a systems analyst. I find it difficult to provide a sentence that sums up who I am because I do not feel that I have known who I am since my Dad died. I intend to speak about my Dad, **GRO-B**. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our family.

Section 2. How Affected

2. When I was 9 we moved house and that's when my Mum first started to notice that my Dad, lacked energy. I didn't really notice at the beginning because I was a child.

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3. At the start of his illness, I was told that my Dad had pernicious anaemia. Both his Mum and her Mum had pernicious anaemia and they received medication so I thought that maybe this was genetic. I wasn't that concerned because I thought that he could be given the same medication as my Granny and Great-Granny (Nanny) and he would be okay.
4. Then I noticed that he started to get sicker in 1980. I remember being told that pernicious anaemia had a one in four likelihood that it would develop into acute myeloid leukaemia and that, unfortunately, was what he now had. He then started to be admitted to hospital more frequently. Once he started to receive treatment his illness became a lot more obvious. Whenever his platelet count was higher he would look better and be more himself and then he would go downhill again.
5. As part of his treatment, Dad received both platelet and blood transfusions. As we did not know at the time that he had been infected we do not know how he was infected. Whenever we visited him in hospital he was always connected to various drips. As a child you don't really ask questions about the treatment being received or the safety of it, you just sort of assume that your Dad is in the best possible place.
6. My Dad was only ever treated at the Edinburgh Royal Infirmary, other than some dental work that he had done elsewhere during his treatment for acute myeloid leukaemia. He also had a respite period at the Astley Ainslie.
7. I know that my Uncle GRO-B and my Uncle GRO-B were tested to see if they could donate but I don't know whether they donated platelets or blood. It turned into a big family joke because my Uncle GRO-B passed out on my Dad's bed, because he was so scared of needles. Despite this he continued to donate for my Dad's benefit.

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8. My Dad died on Saturday the GRO-B At the time of his death we were unaware that he had contracted HIV. On his death certificate the sole cause of death is recorded as "acute myeloid leukaemia." I remember thinking, as an adult, but before we found out about the HIV diagnosis, that this was strange given that there is very rarely one sole cause of death in cancer patients. I also remember thinking to myself that we were told when my Dad died that the cause of death was a massive brain haemorrhage. This wasn't recorded on his death certificate.
9. I didn't find out that Dad had contracted HIV until 10 years after his death. My Mum took my Sister, GRO-B and I out to the Caprice restaurant for a meal. After the meal we got into the car and she gave my Sister and me an envelope each. She told us that my Dad had been infected with HIV through a blood transfusion and that the envelope contained compensation that Dr Ludlum had managed to get for us.
10. I have never been tested for HIV to my knowledge or received any information or advice about it. I do not believe that my Dad was ever told about his diagnosis.

Section 3. Other Infections

11. I do not know whether my Dad received any other infections as a result of the blood transfusions. When he was in hospital my Dad was always across the corridor from the rooms of people who had Haemophilia and they all had individual rooms. My Dad also had his own room but I don't know if this was because his immune system was compromised by the cancer, because he had contracted HIV or because he had also contracted Hepatitis C. My Dad was a very pale grey colour when he was ill. I think he was jaundiced, but if I was trying to say what colour he was I wouldn't say that he was yellow; he just wasn't the right colour.

Section 4. Consent

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12. I do not believe that Dad ever consented to be tested for HIV. I do not know whether he received any treatment, but if he did, I do not believe that he consented to that either.
13. At the time of his death I wasn't at all suspicious, I just thought that Dad had died of a massive brain haemorrhage resulting from the acute myeloid leukaemia. With hindsight however, I think that the new experimental American treatment that he received just before he died, was suspicious. I now wonder whether he was being treated for cancer or HIV at that point.
14. I know that there were patients treated by Dr Ludlum whose medical records were marked with "AIDS Study." I sometimes wonder whether my Dad was one of them and whether he was actually infected by a transfusion at all or was instead deliberately infected with HIV as an experiment.
15. My Dad's illness was my first experience of hospitals, so I don't know if I would have thought twice about anything that was happening because, to me, it just seemed normal.

Section 5. Impact

16. My Dad was my rock and he understood me implicitly like no one else could. He was my best friend. I think that this was, in part, because we both had very logical minds. He worked with very early computers and I work as a systems analyst. As a child I just assumed he would always be there, and that if anything went wrong I could just go to him and he would give me a cuddle and everything would be alright. Then one day he wasn't there anymore. I feel I have been robbed of a large portion of my childhood, and my life, as it has never been the same since he died.

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17. Before my Dad got ill he worked full time and was very active. He cared about his health, he didn't drink or smoke, and loved to take the dog out and run around. We had a close family and he took a very full part in family life.
18. As I do not know when Dad contracted HIV or the impact that it had on his health, I have outlined the decline in his health from the point of his diagnosis. I do not know, and may never know, the impact that HIV had on his health or his ability to recover from the leukaemia.
19. Once Dad was diagnosed it was very obvious that he had no energy. His personality changed and he became very withdrawn. He didn't really want to see us, which was hard to deal with as a child. I don't know how much he knew about what was wrong with him or his prognosis, but as time went on the illness took its toll on his spirit.
20. Dad had very bad oral thrush. I know that he took medicine for it, but he also used to put lolly sticks down his throat and curl the goo in his throat around them before pulling it out.
21. Dad lost all of his hair when he was ill and he also lost a lot of weight. I remember being told as a child that we were going to buy him a new wardrobe because he needed to look more 'trendy'. I know now that it was because none of his clothes fitted him anymore.
22. I remember that my Mum had sent us to chickenpox parties as children but neither my Sister nor I had caught it. Then, when Dad got ill, we both came down with chickenpox so we couldn't visit him. At one point when he was in hospital and we went to visit, we had to put masks on to see him. I do not know if this was because they thought that we would infect Dad with something or whether they were worried that he would infect us.
23. My Mum doesn't remember telling my Sister and me, but during Christmas 1982 we were told that my Dad had a 10% chance of making it through Christmas. Fortunately he did make it through.

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24. I don't remember when it was, but I remember Dr MacCleod coming to the house to show my Mum how to look after my Dad, when he was home. I remember that there were so many needles, a special waste bin, gloves and a fridge full of drugs. My Mum had to administer drugs to my Dad at least once a day through his Hickman Line. I think my Dad had AIDS by this point. This is both because of his symptoms and the fact that Dr MacCleod did not want to treat him.
25. My Dad went into remission on more than one occasion. He went back to work in May 1984, but then he went downhill again. He received a new round of treatment and was really ill, but Dr Ludlum said that he had gone back into remission. We planned a family holiday to help him recover when he finished that round of treatment. Just before we were due to go on holiday my Sister and I were staying with my Grandma for the weekend. We got a call from my Mum telling us to come into the hospital, but when we got there my Sister and I were pulled into a side room by a nurse.
26. The nurse told us that our Daddy had gone to heaven. I remember that I had a big pink comb in my hand and I was twisting it round and round. I said to her that I didn't believe her. I think that on some level I have remained trapped in that moment of not believing that my Dad is dead.
27. My sister ran out of the nurse's room and into the room where our Dad was lying. She then ran back out again very quickly. I went into the room to see Dad with my family. The hospital hadn't even shut his mouth or eye's. He was lying there in a sort of death throw position. It was very distressing; I was only 13 years old at that time.
28. I went to Dad's funeral at GRO-B Crematorium, which I think was on the day that we were supposed to go on our family holiday. It was a Saturday. I remember watching the hearse pulling around the corner and I just started crying. My GranDad told me to stop crying and I couldn't understand why I wouldn't cry when my Dad's body was in a

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hearse in front of me. The crematorium was packed and people even had to stand outside. Dad was very well respected at his work and people had travelled from all over the country to attend, some flying up from London. After the ceremony I was still crying and my Aunt GRO-B told me to have a cream cake and everything would be okay. I remember thinking that, firstly, I wasn't sure how a cream cake would help the fact that we'd just cremated my Dad and secondly, I was lactose intolerant.

29. We started to go to church as a family when my Dad got ill. My Mum had gone when she was a girl, but I don't remember going as a child before Dad was sick. After my Dad died, my Mum and I started to go to a different church. I feel like I am angry at god and I don't understand why he couldn't kill some murderer or rapist instead of my Dad. I remember I met a girl in a bar whose Dad had abused her; we just couldn't understand why it couldn't have been her Dad who died instead of mine.
30. My Dad died at the beginning of the summer holidays, so my sister and I had around 6 weeks before we needed to go back to school. I remember being sent out of class on the first day back so that the teacher could tell the rest of the students about Dad's death.
31. I was very withdrawn following Dad's death. My Mum had a habit of playing songs which reminded me of my Dad and I would just have to leave and cry. My world collapsed. I do not know if I could have coped at all, if I had known that my Dad had been infected with HIV, AIDS or Hepatitis C at the time.
32. I left school in July 1989 because I thought that going on to further education would have been too much of a financial burden. I think that if my Dad hadn't died I would have gone on to the university because I would have had the emotional and financial support to do so. I had no idea what I wanted to do when I left school. My Mum didn't work so she didn't really know about jobs and careers, but I know that my Dad would

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have helped. When I went to see the careers advisor at school, I was just told that I wouldn't get a job in any of the things that I was interested in. So I just got a job and I feel like I'm still doing that job, not really knowing whether it's what I should be doing or not. I have always worked because I was determined to stand on my own two feet, I didn't want to play the role of the victim.

33. I was only a child but I know that my Dad's death had a significant financial impact on my Mum. Someone from my Dad's work came to explain about her pension options. He wasn't a financial advisor so I don't know why he thought he should have been giving advice. I think if he had explained the options properly my Mum would have taken the larger pension, rather than a lump sum with a very small ongoing pension.
34. It was fortunate that my Mum and Dad owned their home because if they had been renting then I don't know what we would have done. Dad was forward thinking enough to have life insurance which covered the mortgage and ensured that we had somewhere to live.
35. I don't feel like I have that many deep friendships because I always feel like people either die or disappoint you. I lost a lot of my childhood friends after my Dad died, because I withdrew into myself so much. The exception to this is that my husband and I have had a very long relationship. Having said that, I feel like I am trying to build a family without the experience that I need to build it on. It's like a no man's land. My husband and I are trying to make sure that my Son has a normal life, but neither of us had a conventional upbringing to build that on.
36. I don't remember exactly when, but during my Dad's treatment for cancer the local Doctor's surgery, the GRO-B Surgery, took blood from me and my sister. They said that it was because they thought that we were anaemic. I don't think they were looking for anaemia however, I think they were testing to see if we had AIDS. The nurse was petrified, and when she couldn't get blood she ran out of the room crying until

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someone else came in to take the blood. I do not know if this appears on my medical records, but I intend to find out.

37. Just after my Dad died I was diagnosed with scoliosis. I had a spinal fusion for scoliosis a few years later, which means that my spine is fused with the exception of four moving disks at the bottom. Sometime after the operation, they were trying to find the records of that operation and they told me that they couldn't find my medical records. When the records turned up I was told that the reason that the records couldn't initially be found was something to do with digitisation. I have always wondered whether there was another reason that my records went missing.
38. When I was around 20 years old I found a lump in my breast, this was particularly distressing because of what had happened to my Dad. When I went to see the specialist the first thing that they said to me was "you're GRO-B's daughter, is that right?" I found this very strange given the length of time since Dad had passed away. After I was examined it turned out that I had swollen lymph nodes, I believe that this is a symptom of advanced AIDS but as far as I'm aware I was not tested. This experience made me think that my Dad was a test subject in some way I don't understand why they would otherwise remember him so long after his death? Are my records also marked in some way?
39. There is definitely a stigma attached to having HIV or AIDS. I have been in situations where someone had been talking about how AIDS is a gay disease and I have to put them right. I have told my Manager at work and a couple of my co-workers about my Dad, but I don't tell many people. My Mum didn't really tell any of our family. I think that part of this is the stigma, but part of it is that I don't think other people will believe me if I tell them. If we had the records that told us what happened then maybe it would be easier and we could move on.

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Section 6. Treatment/Care/Support

40. Dad was never told that he had contracted HIV so I do not believe that he received any treatment, care or support for that virus.
41. We weren't offered any counselling at the time that Dad died. I think that my Mum went to visit Dr Ludlum years after Dad died and Dr Ludlum referred us to somewhere in Edinburgh for family counselling. My Sister didn't like the therapy but I agreed to go back. When I went to my appointment, which I had taken a day off work for, I was told that the therapist was on her day off. I gave up on counselling at that point.
42. When I found out, 10 years after his death, that my Dad had contracted HIV I was not offered any counselling, although, I think that there may have been some kind of drop-in support clinic, but I didn't really have any details about it. This was likely mentioned on the form I had to sign to keep quiet about it.

Section 7. Financial Assistance

43. I was given an envelope by my Mum which contained a cheque. This was compensation for the fact that my Dad had been infected. We had to sign a form to say that we couldn't tell anyone what had happened and couldn't pursue any further legal action. I do not remember if the form that I signed said anything about legal action regarding Hepatitis C. When I signed that form I felt that it had just been a simple blood transfusion accident, now I feel like that wasn't the case. When I signed the form I didn't really know what I was being asked to not talk about; was it that my Dad had suffered from a transfusion induced infection or was it that he had been part of an AIDS study? I received the money on the 22nd of September 1994.
44. I did not know that there was any legal action in relation to compensation for the HIV infections and I did not instruct a solicitor.

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Despite this, when we were given our cheques, the solicitors had taken £293.75 out of each of our settlements. I don't really understand how I paid solicitors that I had never even instructed.

45. I believe that my Sister and I would have been eligible for support with further education if we had been told earlier that my Dad had contracted HIV. However, by the time we found out it was too late for all that as we exceeded the age limit. We could both have benefitted from this if Dr Ludlum had told us either when Dad was ill or when he died.
46. My Dad died before the MacFarlane Trust paid us our compensation so he has never received any compensation himself, or via his estate. I presume that in families where the infected individual was alive the individual *and* the family would both have been compensated. I don't understand why we get less because Dad had died. His pain and suffering has not been compensated.
47. I found out about the Scottish Infected Blood Support Scheme (SIBSS), because I had been monitoring the Scottish Government website. In May 2017 when I was on the website, it said that the system had changed so I emailed SIBBS about whom I was and who my Dad was. My Mum didn't want to fill in the forms, but they were very simple. All they wanted to know was her name, her bank details, Dad's death certificate and a confirmation that she had not remarried.
48. I do not receive anything from SIBSS.

Section 8. Other Issues

49. At this time I have not campaigned on this issue nor have I been legally represented.
50. I have a number of questions which I would like to be answered about what happened to my Dad. I have set these out below.

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51. Was there any experimentation / research on a test group of Edinburgh Patients being given a virulent strain of HIV by Doctor Ludlum? (He may have operated wider afield than Edinburgh Royal Infirmary)
52. If so, was my Dad one of these Patients in the Test Group?
53. Why were patients not informed of their HIV status? Also, their families didn't know about their infected status which put them at risk of infection. Why was this hidden and why were family members put at risk? This feels very underhand.
54. Are there still copies of my Dad's medical records?
55. Are there still copies of my medical records?
56. I would like to know whether the Inquiry will pull copies of all of the research and publications by Dr Ludlum.
57. I would like to know whether the Inquiry will look into Dr Ludlum offering his patients up for an AIDS study to Dr Robert Gordon following an article in the Lancet (1983).
58. I would like to know whether the Inquiry will be looking at the medical notes of those patients who had their notes marked with 'AIDS Study'.
59. Were records deliberately destroyed to hide what happened? How wide spread was any such destruction?
60. Why didn't my Dad's death certificate mention HIV/AIDs or even the massive brain haemorrhage which killed him?
61. Why was there no provision to support families of victims after the date of death of the infected individual until the scheme in 2017? Why was there no backdating introduced when the 2017 scheme was introduced?

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62. Did my Dad contract Hepatitis C?
63. If my Dad had also contracted Hepatitis C this would have altered our entitlement to compensation. If my Dad's records no longer exist how will it be addressed that we cannot prove whether or not he contracted Hepatitis C?
64. Was the blood test I received when I was about 12 to look for anaemia or were we being studied / tested for AIDs?
65. Were we, as a family, being monitored to see if we contracted AIDs from my Dad? (This seems likely as, when I had a breast lump checked about 8 years later at the hospital, the Consultant opened the conversation with 'you're GRO-B's Daughter.' Why else would he say this?)
66. When all this was happening, we as a Family were registered at the GRO-B Medical Practice. The main Doctor's we saw were Dr Alex MacLeod and Dr Brown. Will the investigation be speaking to these Doctors as I expect Dr MacLeod will have clear memories of our situation? These Doctors must have known Dad's status and also never shared it with us.
67. Overall, my question since I found out about his diagnosis had been what happened to my Dad?

Statement of Truth

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

Signed

GRO-B

Dated

16th MAY 2019.