

Witness Name: **GRO-B**

Statement No.: WITN0781001

Exhibits:

Dated: 7<sup>th</sup> February 2019

**13 FEB 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 10<sup>th</sup> January 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 mother to an 11 year-old girl and, having previously worked in the care industry, I am now a teaching assistant. I intend to speak about my Dad. In particular, the nature of if his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

**Section 2. How Affected**

2. As a child you pick up on some things in the adult world and you are told some things, but you aren't necessarily aware of everything that's happening around you. I know that there was a period before my Dad

received a diagnosis, this must have been when I was around 7, where he had no energy and he clearly wasn't well. I think he had an initial doctor's appointment, which he went to with my Mum, but once he was diagnosed with acute myeloid leukaemia he was treated at the Edinburgh Royal Infirmary. I was 8 when he was diagnosed.

3. I have a clear recollection of being in the hospital when my Dad was ill. He had a stand next to him and there would be a bag of blood and a bag of clear fluid that would be going into him. I remember it very clearly because it really freaked me, out as a child, that I could see the blood going into him. I would stand there and stare at the blood. That's why despite only being around 8 or 9 years old I remember that so clearly. Even today I am quite scared of getting blood tests and I feel it's related to that experience as a child. My understanding is that the clear fluid was platelets and that these came from my uncle, my Mum's brother, rather than having been donated by the public or imported.
4. I would have had it explained to me that my Dad needed the blood transfusions because of the leukaemia. I don't remember the exact explanation I was given, but I think it was because his red blood cell count was low. I also know that leukaemia affected the white blood cells though so it may have been to do with that.
5. I imagine it was one of these blood transfusions that infected my Dad with HIV, but we do not know which transfusion and so we can't be sure which year the infection occurred. I remember that my Dad used to be in a room on his own a lot of the time. I think that I saw him on a general ward once, at the beginning of his illness. As a child I didn't think anything of that but now as a family, looking back, we aren't sure, maybe that was a wee bit odd and maybe that was because he had already contracted HIV. People don't generally get a room of their own unless things are pretty bad but he tended to have one throughout his illness. I believe that he started to experience severe symptoms shortly

before his death in 1984 as there was a sudden decline in his health, which is outlined further in the section on impact below.

6. My Dad was treated by Dr Ludlam for his leukaemia and Dr Ludlam was a household name in our home. My Mum talked to him a lot and he had a major role in my Dad's treatment but also more generally in our house. I remember that my Mum was on first name terms with him and called him Chris. He didn't just talk to my Mum about my Dad's illness, but he also did things like advising her to book a holiday shortly before my Dad's death. Everything that Dr Ludlam said was incapable of being questioned (at that time), my Mum really trusted him.
7. I do not know why my Dad was not told that he had contracted HIV and I think it was disgusting that he was never told. Because he didn't know, he did not receive any guidance on how to deal with the infection, the impact it would have on his health or how to avoid transmitting it to others. I do not know what was known about these issues at the time however, it makes no sense, not to have told both my Dad and his nearest and dearest given the risk of infection; it comes down to playing God with people's lives. I think that Dr Ludlam assumed that my parents weren't having sex because my Dad was so ill, but the situation was too dangerous to make any sort of assumptions like that.
8. There were times when my Dad was home with two young children and a wife who was having to perform invasive medical procedures on him; the risk of any of us being infected was so high. We were never given any indication that my Dad was ill and we weren't told to be careful around him or avoid contact. My Dad lost his hair while he was ill, which he found particularly difficult and I would get on his knee for cuddles and brush his head with this soft hairbrush. He used to say that that made him feel better. I kissed and hugged him as you would as a child. I have wondered whether we were being watched, as a family to see if any of us contracted HIV.

9. There was a Christmas, I don't remember exactly when, but my Dad was critically ill and when we went to visit him, I remember that we were asked to put masks on. At the time I think we all assumed it was to protect him from any childhood illnesses we might accidentally pass on, although if we were ill we weren't allowed to visit. At the time my Dad had a horrendous cough and he was coughing up blood into a metal dish. I remember that my uncle GRO-B made a joke about cowboys and spittoons and as a child I'd never heard the word spittoon before so it stuck in my mind. I have wondered since whether we were asked to wear masks because he was coughing up blood and there would have been particles of blood and spit in the air. The problem with having not been told about the HIV until eight years after my Dad's death, is that once you find out something like that, you re-question everything you've been told in the past to try and establish when he was infected and the impact that it had.
10. I don't know whether having a brain haemorrhage is a normal way to die from leukaemia but I find it odd that the only cause of death on his death certificate is a brain haemorrhage. The certificate doesn't mention leukaemia at all, despite the fact that that is supposedly how he died. I thought that death certificates were supposed to list all causes of death. There is no mention of either HIV or AIDS on my Dad's death certificate.
11. It wasn't until I was 18 that anyone in our family knew that my Dad had been infected. My Mum had a chance meeting with Dr Ludlam in the hospital and I believe that he had a stab of guilt that he had never told her about my Dad's infection. He phoned her shortly after they had met at the hospital and asked her to make an appointment with him. Dr Ludlam told my Mum that my Dad had contracted HIV and he asked her if they had sex while my Dad was ill. I know that my Mum was in a

state of shock especially because she had to have a HIV test, which was thankfully negative.

12. Although all of the information was relayed second hand from my Mum I get the impression that Dr Ludlam was very matter of fact in the way told her. He also told her that there was a court case and that he would complete some paperwork for us so that we would get some money. I think he made out like, he was doing the right thing and doing us a favour by telling us, so that we could receive the money. It diverted the focus from what had happened and how my Dad had been infected to how Dr Ludlam was going to fix it. I can't speak for my Mum, but there are a lot of questions that should have been asked and I was never given the opportunity to ask any of them. There was no explanation of how it happened or what the consequences were. I don't feel like it was ever explained.
13. I think that my sister and I should have been involved when my Mum was told. I don't think I saw it as an option that I could or should have asked to talk to Dr Ludlam at the time. I think that if I tried to talk to him now, I don't know how I would react but maybe back then, when we first found out it would have helped. Having said that though, I don't know if he would have answered any of the questions that we would have asked.

### Section 3. Other Infections

14. I believe that my Dad may have contracted Hepatitis C as well as HIV. When my daughter was born she was slightly jaundiced and that was the same colour that my Dad was before he died: he had a yellowy sort of pallor. I don't know if the discolouration of his eyes or the haemorrhaging of his eyes was also indicative of Hepatitis C. I don't think we will ever know for sure unless we can obtain a copy of his medical records.

**Section 4. Consent**

15. I think that my Dad was definitely tested for HIV without his knowledge or consent. I do not know whether he was ever treated but if he was I don't think that he had knowingly consented to the treatment.
16. The issue of whether research was conducted on my Dad torments me. I think there is a question of how people were infected and I know that there are people who question whether that infection was negligent or deliberate.
17. I can get my head around the fact that my Dad may have been negligently infected but I can't really get my head around it if Dr Ludlam decided that he was going to conduct some sort of case study by infecting individuals.
18. Obviously if Dr Ludlam had patients who were already infected and he decided to do a case study on disease progression or treatment then that is something that I want to know about. I find it personally so horrific that my Dad could have been studied without his knowledge that I don't even know how to express how I feel about it.
19. For me the fact that there were samples taken from my Dad and then kept for a decade after he died, indicates that Dr Ludlam knew about the illness when my Dad was alive. I don't believe that my Dad was asked if samples could be taken or kept. I expect that he was told that the samples were being taken because of his leukaemia and not for HIV testing. Perhaps he just assumed that it was a routine procedure and no one had ever explained anything at all. I do not know what has happened to those samples or where they were/are kept.
20. I think that if you're involved in research you have to be provided with information about the risks of any treatment or procedure and that didn't

happen. I think that the issue of consent is difficult because when you are that ill and you are offered something that might help, you will say yes. I can't begin to imagine what my Dad was going through thinking that he wouldn't be there for his wife and kids. He must have been very down and angry at times and that's without knowing about, what was going on, regarding his HIV status. My heart breaks for him that he never knew what was happening to him.

21. I know that my Dad was given an experimental chemotherapy treatment. It occurs to me now that we do not know whether that was a treatment for his leukaemia at all, it might have been a treatment for AIDS. I don't know if there were any treatments available at the time of my Dad's diagnosis.

#### **Section 5. Impact**

22. I totally adored my Dad and he was a brilliant Dad but I didn't feel like I got enough time with him, because he died so young. I struggled for a while to think of memories of my Dad before he was ill. It was such an intense period of time that I couldn't remember happy things and I really struggled with that. Now I remember that on a Friday nights, before he was ill, he would go and buy singles from Woolworths and do a disco night for the family. We had ballet lessons earlier that day and would be prancing about the living room in the evening, still in our ballet gear while he DJ'd. He loved all sorts of music and that is something we had in common. We also used to go on family holidays and on daytrips to the seaside. As a family we would go to Gullane and there was a special place that my Dad used to like to go and sit on the rocks. We would have packed lunches and paddle in the sea.
23. Those happy family experiences and the cohesiveness of our family all changed after my Dad's illness and death. Our family was very important to my Dad. Once during his illness when he was particularly sick I remember he had a conversation with my sister and me about

how ill he was. He told us to look after our Mum if he wasn't there for us.

24. On one occasion when my Dad was ill he came from hospital to stay at home for a few weeks. I remember that Dr. GRO-B who was our family GP, came to the house to show my Mum how to administer the medication to my Dad and then he just left her to it. The sideboard in our house was full with medication and medical paraphernalia and we had a special bin in the kitchen to put needles and medical waste into. When my Dad needed his medication my Mum would lay it all out on a kitchen tray and then inject it straight into his Hickman Line. I remember it so clearly because it made me feel quite squeamish. I remember that sometimes when my Dad was upstairs in bed my Mum would go up and see him with trays, some of them had food on them and some of them had medicine. Looking back on that now that I am older I find it so scary. My Mum didn't have medical training and should not have been responsible for my Dad's medication.
25. Although we do not know and may never know how the HIV affected my Dad's health I know that there were differences between his illness and that of my cousin who also had acute myeloid leukaemia. Even shortly before my cousin passed away he looked a lot 'better' than my Dad had.
26. I was in my late 20s when I watched a documentary about people with AIDS. I remember I was in my flat in Edinburgh and I completely fell apart, because these people with AIDS just reminded me of my Dad. I don't remember all of the similarities now between the people in the documentary and my Dad, but it was things like the recurrent thrush in his mouth, his skeletal appearance, sunken face and slight jaundice. I'm also not aware that a hacking cough is part of the normal trajectory of leukaemia but that was something that my Dad suffered with a lot.



27. Because I was a child I find it difficult to place events clearly on a timeline of my Dad's illness. However, I remember at one point his cancer had gone into remission and we thought he was going to be ok. He started to look a bit better. After that he went downhill very quickly. I have always wanted to know whether that sudden decline was the AIDS, but I do not have the medical knowledge to know what happened. I understand that it could simply have been the leukaemia.
28. One of the trains of thought I always have, is what chance did he have to fight acute myeloid leukaemia with HIV or AIDS as well. I believe he had a chance of surviving the leukaemia but that this was compromised by the fact that the HIV or AIDS attacked his immune system. I think it must have been a death sentence for him.
29. One of the things that intrigues me, is that Dr Ludlam seemed to know how my Dad was going to die. He kept saying to my Mum that if his eyes haemorrhaged that he needed to come back in urgently. I feel like, as a child I also knew when my Dad would die. I remember that the weekend my Dad died my sister and I were sent off to my grandparents' house, to give my parents some peace. It was clear even to me as a child that my Dad was very very ill. When we said goodbye, at my grandparents' house I burst into tears and I thought this was the last time that I was going to see my Dad. I don't know how I knew, but I was clinging onto him and crying.
30. We got a phone call that weekend saying that we needed to come into the hospital. When we got there my Dad was already dead but we didn't know that. GRO-B and I were taken into a little room and left there. Then the sister came in and said to us that our Daddy had gone to the angels, or something similar. It was so awful because it was just the two of us. My sister just kept saying "I don't believe you" over and over again like a mantra. I kept saying that I wanted to see him and when I

saw him I completely freaked out and ran out of the room. It was absolutely horrible.

31. When you look back on these things, it's very odd to tell two children that one of their parents is dead when they haven't got anyone with them for support. I didn't have anyone there to give me a cuddle or to tell me anything. I don't know how it could have been done differently but I think that it should have been done differently.
32. I also think that my sister and I missed out by not being able to say goodbye to my Dad that day. I know my Mum had been told to look out for my Dad's eyes haemorrhaging but I don't think she realised that meant, that it was the end. This was especially true because Dr Ludlam had told her to book a holiday for the four of us the following week. I think that in the circumstances none of us were prepared for his death and that could have been handled better.
33. My Mum says that Dr Ludlam took some students in to see my Dad hours before his death. I find that very weird. Dr Ludlam knew my Dad was at death's door, so either he was incredibly insensitive or there was something suspicious about that.
34. Losing my Dad has devastated my life in a number of ways and my opinion about what has happened and how it has impacted my life has changed a lot over the years. In some ways it is harder now than it was then, because I feel now that I have lost my Dad in lots of different ways. I think that that is a natural part of grief because if you lose a parent as a child it feels like you lose them again every time there is a milestone and they aren't there. I remember falling apart when I was pregnant with my daughter, because he would never know her and she would never know him. Grief is a strange thing because it doesn't just exist in the past. It comes with you through your life and changes and evolves.

35. Being 10 when he died was horrendous. For a very long time I thought my Dad died the year I went to High School but he actually died when I was in primary 7. I feel like I lost a whole year of my life and I don't remember anything about that year at all. I know that for the two years of his illness I struggled to concentrate at school because all I could think about was what was happening to him and this feeling of distraction at school continued after he died. I came out of school with qualifications, but I know that his illness and death had an impact. After school I did a diploma in art and design at college and then I went into care. I was told during some work experience that I should become a nurse but the medical side of being a nurse creeped me out, it was all of the stuff I had seen being done on my Dad and I didn't want to do that.
36. Our family dynamic radically changed when he died and it has never been right since then. I love my Mum very much and she has had a very difficult time and has found it hard to cope. She was a good Mum and she made sure that all of the practical things were taken care of; we were always well fed and she made sure we went to school. However, I feel like our family was broken and that my Mum and my sister have been very rooted in their grief. Within the family there was always a focus on my sister's relationship with my Dad and it sometimes felt as though my grief was invisible. At times it felt like I had lost my Mum as well as my Dad and that my Mum, my sister and I were all in separate bubbles of grief.
37. I am sure that I felt anxious when my Dad was unwell but it was worse after he died. I felt very alone and that feeling of loneliness has persisted in a lot of ways throughout my life. I often feel isolated in what I am going through and that I can't express how I am feeling. I developed psoriasis on my scalp when I was around 10, this still flares up when I am stressed or emotional, I do not know if that was a physiological side effect of my Dad's death.

38. I developed a lot of anxiety that my Mum would die. I remember on one occasion my Mum went to visit one of our neighbours and she didn't come back, when she said she would. I was so frightened that something had happened to her. I think that I felt responsible for my Mum and as I entered adulthood there was a battle between feeling responsible for my Mum and needing to take care of me.
39. It is obviously very hard to think about what could have happened if my Dad had not died. What I do know is that not having a father in my life has impacted me in various ways and I am sure that life would have been easier with him in it. One example of this is that I have struggled with having some destructive relationships and maybe if my Dad had been there, he wouldn't have let anyone treat me like that. I don't feel like I've had that person there fighting my corner or protecting me.
40. We certainly weren't well off as a family after my Dad died. I got hand me downs from my sister and was bullied for wearing them. We would get things from jumble sales and charity shops and I knew that my Mum was always worried about money. I think that when I was really small, before my Dad was ill, I wasn't tuned into the financial side of things, but we were well looked after. He was just getting to the point in his career where things would have been financially easier when he got ill.
41. I was 18 when I found out that my Dad had been infected with HIV or AIDS. It completely unhinged me. Finding out that he may never have died if he hadn't contracted HIV, put me into a total downward spiral. My Mum said that I wasn't allowed to talk to anyone about it, which made it more difficult. This was partly because we had to sign a document to say that we wouldn't go to the press in order to receive money from the litigation that Dr Ludlam had undertaken, but I think it was also the stigma.

42. I think that, on some level, my Mum was mortified by the stigma of my Dad having contracted HIV. I know that back in the 1980's when my Dad must have been infected that AIDS had just hit the press. It was in the newspapers all the time and there was a huge drive providing information about safe sex, where you would get leaflets through your door. There was a lot of misinformation and a lot of people had misconceptions about the illness; the fear was phenomenal. You would go into bathrooms and there would be graffiti on the walls telling you not to sit on the toilet seats because you would get HIV. I remember it being referred to as the "gay plague" and I think that that was a way for people to distance themselves from HIV and AIDS. It was almost as though people thought that it was all right as long as it only affected certain groups of people. Things have moved on and the medication has moved on but I think that people's attitudes haven't really changed that much.
43. My Dad's parents didn't know that my Dad had HIV, because my Mum decided not to tell them. I think it put a strain on my relationship with them after that, because I didn't agree with the decision. I understood why my Mum didn't want them to know, it would have devastated them, but it felt wrong that I knew this and they didn't know it about their only son. My grandparents on my Mum's side didn't know either, which meant that whilst I could share good memories about my Dad with them, I couldn't really talk about his HIV diagnosis or what had happened to him.
44. I think that receiving the money from the litigation when I was 19 or 20 also had an impact on my life. The only upside of the money was that my Mum and I weren't getting along very well, because I wasn't coping with having found out about my Dad's diagnosis, and it meant that I could put down a deposit on a flat and move out. The problem was that people would ask how I could afford the flat and would tell me how 'lucky' I was to have it. I just wanted to shout that 'I wasn't lucky at all' and to explain where the money had come from, but I wasn't allowed

to tell anyone. I felt like there was a lot of guilt attached to the flat and a lot of conflicting emotions about having been given the money. I don't know whether this was made harder by the fact that it all felt a bit grubby because we weren't allowed to talk about it.

45. I don't know how to categorise my mental state when I found out about my Dad contracting HIV but it wasn't a healthy mental state. I began to self-harm. I never did anything that needed medical attention but I hurt myself in small ways. I think I probably was depressed but I had no idea.
46. I tried to kill myself by slashing my wrist when I was 20. It felt like my Mum was angry at me for doing it and I was told again that I couldn't tell anyone about that. She was saying to me that I would never get a job and I remember thinking that a job was the last thing I was worried about.
47. There were other things going on at the time, I had been through a break-up for example, but it wasn't about that, that was just the last straw and I couldn't cope. When I slashed my wrist I was criticised by the staff at the hospital for putting my mother through it and told that I was wasting the time of medical staff. I didn't get offered any help and I don't remember being asked about what was going on in my head. Once again there was no support.
48. Now that the Inquiry is ongoing and everything is being talked about again I'm finding out new things and I feel like I have to go through everything again with a different slant. It's an awful thing for anyone to lose someone that they are close to. It is awful when that person is young. It is awful when that is your parent and you are a child. It feels unfair. It would have been a tragedy if he had died of cancer but to then have the HIV diagnosis thrown into the mix it changes everything. I just don't understand why we were never told whether a mistake was made

or what it was that happened. It is grossly unfair and I have had to live with these unanswered questions.

#### **Section 6. Treatment/Care/Support**

49. I have never been offered counselling. I tried to get counselling on the NHS and I went to somewhere called Wellspring but I didn't have any sort of bond with my counsellor. She would just sit there and I found her very difficult to talk to. The two counsellors I have found who helped me most, were both private and as a result I have spent a fortune on counselling, which I have undertaken at a number of points in my life; on one occasion fortnightly for two years. Some of the money that I received from the litigation was spent on counselling. Whilst I know that there are other things in my life, which have been difficult, I feel like what happened with my Dad has always been at the core of everything. It feels like a rock being dropped into a pond and the ripple effect has been phenomenal.

#### **Section 7. Financial Assistance**

50. When I was around 19 or 20 I received around £19,000. I did not complete any of the paperwork as I believe that Dr Ludlam completed this for us; I don't even think my Mum completed any of the paperwork. Before I received my cheque I had to sign a form and agree, not to say anything to anyone about receiving the money. I also had to agree not to go to the press.
51. I have never been aware of being entitled to anything else. I know that my Mum has recently started to receive ongoing payments from the scotish Infected Blood Support Scheme (SIBSS). I believe that she was entitled to those for a long time, but she didn't know and the payments haven't been backdated.

52. My Mum did receive some sort of pension from Dads work, after he died. I do not know many details regarding the financial issues around the death of my Dad. I believe my Mum has explained them in her statement.
53. I don't know how to assess the adequacy of the money that I received because you can't put a price on someone's life and all I wanted was my Dad back.

**Section 8. Other Issues**

54. I feel as though a lot of the people who are involved in the Inquiry have been infected through haemophilia and that a lot of the media coverage has focused on this. Sometimes I don't understand how my Dad fits into this.
55. I am not currently represented in any legal capacity. I have never been involved personally in any campaigning on this subject.
56. I have been asked if I would like to put any questions to the inquiry, I would very much like to ask the following :-
57. When did my Father contract HIV? (date of diagnosis, and at what stage was his Leukemia at this point in time?)
58. How did this occur? Was it via a blood transfusion? And if so why was effective screening not in place at this time? Why were risks taken?
59. At this point, and on going, what decisions were made regarding my Father's treatment (for both Leukemia and HIV/AIDS)? Was he studied as part of any research, and did he take part (without consent) in any drug trials for HIV or AIDS?



60. Why was this vital information ( ie. his HIV diagnosis) kept from him (my Father) and his family?
61. How did the HIV virus progress in my Father, as a vulnerable patient with an existing blood condition? Did he die due to complications of full blown AIDS?
62. Why were we only informed of these misdemeanours 8 years down the line, and then only to be silenced and left with unanswered questions?
63. Why was there no support or counselling offered?

**Statement of Truth**

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

Signed

GRO-B

Dated 07.02.19