

ANONYMOUS

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN0962001

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 02 September 2019.

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

Section 1. Introduction

1. My name is **GRO-B**. My date of birth is **GRO-B** and my address is known to the Inquiry. I am a Learning and Teaching Development Manager at **GRO-B**. I am the second eldest daughter of **GRO-B** and have two sisters and two brothers. I intend to speak about my father, **GRO-B: F**, who contracted HIV and HCV as a result of contaminated Factor VIII products, or possibly blood transfusions. The HIV developed into AIDS and he eventually died on **GRO-B** 1987 as a result of liver failure. In particular, I intend to speak about the nature of his illness, how the illness affected him and our family, the treatment he received and the impact it had on him and our lives together.

Section 2. How Affected

2. My Daddy had severe haemophilia A. He was one of four brothers and all but one of them had haemophilia. I don't know how or when he was infected as he had so many treatments of both Cryoprecipitate and Factor VIII. He used to get Cryo at Altnagelvin Hospital, [GRO-B] but then he was moved to Factor VIII. I remember that as there was great delight in our family when he moved to Factor VIII. Mammy trained to give him the injections and it meant we could sometimes deal with any bleeds at home. It also meant he wouldn't have as many hospital admissions.
3. As a child my Daddy told me and my sisters that we were princesses. He also told me that he would be the next king of Ireland once it was free. I had no reason to doubt him because he had also assured me that he had blue blood. The fact too that he suffered from haemophilia, which is known as a 'royal disease' confirmed our royal status. I wasn't always entirely sure that I really was a princess because I didn't possess any of the necessary trappings. Then one day, I noticed that the brass candlesticks at either end of the mantelpiece in our living room were inscribed with the words 'Diamond Princess.' This clinched the deal for me; we lived in [GRO-B] in the city centre of [GRO-B] so obviously I really was a princess. There was never any doubt in my head that my father was a king.
4. As children, we didn't always have a babysitter so we spent a lot of our time in the hospital grounds while daddy was in hospital. It became a bit like our playground! We lived opposite a convent and very often it would be the nuns who would come in the evenings to babysit us. Mammy and Daddy would regularly be out of the house in connection with Daddy's health.

ANONYMOUS

5. I recall there was one year for sure, he spent at least a day every week in hospital. Sometimes, he had a bad temper but we knew that was because he was in an enormous amount of pain from the haemophilia. My Daddy had a very hard life. As well as the illness, he carried a broken heart, having found his mother after she took her own life when he was 7 years old. I remember Daddy always having a limp, which was a result of the haemophilia and its impact on his joints. His brother, GRO-B, also had a limp. They were all crippled with arthritis. However, Daddy always tried to make the best of it. He rarely, if ever, complained.
6. We couldn't really ever know when he got HIV. I was at GRO-B University, GRO-B and I came home around June 1986 and found a letter in the kitchen from GRO-B Hospital, GRO-B which had already been opened. I looked at it and it said "HIV, Non-A Non-B" on it. It was written formally and starkly on the letter, something like: "Dear F the results from your test have come back positive. If you want more information, please contact us. Dr GRO-B" That's how I found out but I didn't disclose that I had looked at the letter because I knew it was something myself and others weren't meant to know.
7. I was aware of the implications of this as the shocking plight of AIDS patients was rarely out of the news. The reactionary rhetoric and the holocaust hysteria had begun to take hold. Nationwide leaflet drops and a massive government sponsored media campaign depicted tombstone images and nurtured fear, condemnation and stigma.
8. I reacted with a strange mixture of shock and confusion. In an attempt at cognitive dissonance, I told myself that this really meant "it is positive that you do not have it." But I knew that really it was a death sentence. I'm pretty sure of the date as it was after my first daughter was born in 1985. I think my parents and certainly my daddy must have found out for the first time via that letter as well.

ANONYMOUS

9. Later, we made some more enquiries and through freedom of information requests, Mammy received some documents and letters. In one of the documents, Dr [GRO-B] is writing to someone else and she wrote in the letter that it had been confirmed with Daddy that he had HIV in June 1986 but that he had the symptoms maybe 2 years before that. I don't know if anyone had approached him about this infection before 1986 though.
10. Daddy never drank alcohol in his life. He was teetotal, as was Mammy. He had no tattoos nor did he use intravenous drugs. I am not aware of any blood transfusions or major operations that Daddy underwent. His brother, [GRO-B] who was also a haemophiliac died of HIV ten years after Daddy, and [GRO-B] his eldest brother, again a haemophiliac, also has HIV, but miraculously is still alive but very ill. Whilst I can't pinpoint an occasion, it is very clear that Daddy was infected with HIV and HCV as a result of contaminated Factor VIII blood products from Altnagelvin Hospital, [GRO-B] sometime during the 1970s and early 1980s.
11. I don't know if it's relevant but Daddy almost died of hepatitis fifteen years before he actually passed away, so around 1972. There is a possibility that he may have hidden the fact that he had HIV from us and was aware earlier than the letter shows but I don't know about that. Mammy told me that he said to her on occasions "well you don't know everything" as though there were things he did not reveal.
12. I am now aware my parents decided not to tell anyone about it so even though I knew, they didn't tell us. I used to hear them every now and again whispering. We don't know if Daddy even told his brothers despite them injecting Factor VIII as haemophiliacs. As I mentioned above, two of them later developed HIV as well. I don't know if he even told his closest friends or not.

ANONYMOUS

13. When he was diagnosed, I don't think Mammy or Daddy were told about any precautions to take. I don't recall any separation of towels or toothbrushes or anything like that. None of us were tested either or offered any tests.

Section 3. Other Infections

14. I don't believe that Daddy received any infection other than HIV and HCV as a result of being given infected blood products. I think I remember that he got pneumonia at one point but I'm not sure how this came about.

Section 4. Consent

15. I don't know if Daddy was treated or tested without his knowledge, or consent, or for the purposes of research and he may not always have been aware of the actual purpose of a test. In fact, I don't think he was prescribed any medication to deal with the HIV or his earlier HCV. I don't think the doctors really had any idea what to do. It was all so new.

Section 5. Impact

16. Daddy was a very religious man and he was a leader of the GRO-B He went to daily mass and was deeply spiritual. Sixteen priests and the bishop took part in his funeral with forty more in the audience. Even after his diagnosis, I did not notice much change in his temperament. There was no anger or bitterness and I suppose his faith carried him through his bleakest hours. I am sure that he cried many tears when alone but never in front of us.

17. Towards the end, he was very tired and he would have his dinner and fall asleep and then we would have to wake him up as he always wanted to go to his 7.30 mass every evening. We noticed him getting

ANONYMOUS

more tired as time progressed. He lost weight and he also developed lesions on his body and he started to go very yellow at times.

18. I do remember that Mammy became more protective of him from about six months before he died. Just before he was hospitalised, he went on a silent retreat for two weeks in Dublin and I remember Mammy being upset as she didn't think he was well enough to go. He probably didn't drive but he did go.
19. At the end of June 1987, he went to a place called GRO-B which was a week-long retreat for both Catholics and Protestants. This was to be where he made his last public talk. GRO-B my youngest brother, and GRO-B my sister, went with him. I remember that Mammy didn't go, I think as an act of protest because she really did not think that he was well enough to go. All of us went to hear his final public talk though. That was the day that we had to take him home, take him straight to the GRO-B hospital in GRO-B and that was the beginning of the end.
20. After his diagnosis, I am sure that he was in and out of hospital a lot but it's difficult to distinguish the admissions as he was always in and out for his haemophilia.
21. When he was admitted to hospital in the weeks prior to his death when the infection really took hold, Mammy, my elder sister and I stayed with him 24 hours a day in shifts from the end of June to GRO-B
22. During that time, he wasn't, and we weren't, treated very well. We often felt that we were basically left to our own devices. My older sister is a nurse and we were very reliant on her. Initially Daddy went to the GRO-B GRO-B Hospital at the end of June and he was put in a room with four beds and everyone else was moved out of it so he was isolated.

ANONYMOUS

23. Very rarely did we see a nurse. Very, very rarely. The same anaesthetist would come during the night but that was basically it. We were definitely left on our own. I knew this was because people were afraid at the time. We could be there from the morning to the night and basically not see anyone outside the doctor's morning visit. We were wondering what we were doing there as nobody seemed to be doing anything for Daddy or telling us anything about his condition.
24. The fear was evident in the hospital from the way he was treated. He couldn't get out of the hospital bed as he was so weak. I think Daddy was in the [GRO-B] Hospital, [GRO-B] for three weeks and nothing happened treatment or care wise apart from them giving him blood transfusions and his condition deteriorating. Then one day he just said, "I want to go home". I think he knew he was near the end. We asked the doctors and they said no but we said we were taking him anyway. They wouldn't provide an ambulance because it was a weekend but my uncle arranged one through the Red Cross and we were able to take him home to his own bed. The local GP, [GRO-B] came every night to visit Daddy and check on his condition
25. I remember at the hospital in [GRO-B] I asked the anaesthetist what was going to happen to Daddy and he said he didn't know. They didn't know what to expect, which is what all the doctors seemed to think. I asked if Daddy had AIDS and he said "Yes" and that is when it was confirmed to me which was around the end of July or beginning of August 1987.
26. We had him at home for about two weeks with our 24-hour care. He was on morphine and very, very ill. He was dying. I remember the doctors saying if he starts bleeding a lot you won't be able to manage it at home and he will have to go to the hospital. And then one day it happened, he started bleeding and he filled a large bowl with his blood, as I held it. We rang an ambulance in an emergency and we took him to the local hospital. Blood was coming out of everywhere and that was

ANONYMOUS

when we knew it was the end. They were trying to treat him with blood transfusions but his liver had failed and so as fast as the blood was going in, it was coming out again. He couldn't eat and basically went green from the jaundice. Daddy lost loads of weight and the doctors couldn't believe he held on for so long. He had a horrific death.

27. We had taken him to Altnagelvin Hospital, [GRO-B] where again we were isolated. Daddy went into a coma just two days after we moved him from the house to the hospital. His last words to my Mam were "it will be alright [GRO-B]". My Mam is called [GRO-B] I was reminded of this when I heard of the text message Seamus Heaney sent to his wife moments before he died: 'noli timere', which is 'don't be afraid'. These final last words of my daddy have always comforted me and, I am sure, my mammy.

28. He had regular fits during those last five days in Altnagelvin Hospital. This was very frightening for us to watch and we would ring the bell for a nurse when they were happening. I remember, on one occasion, a male nurse came in while he was having a fit and was looking at him from the bottom of the bed and then he literally turned and ran out of the room. Like his time in the [GRO-B] Hospital, we felt very isolated in that small hospital room as very few of the nurses or doctors came near us.

29. I remember about 5 minutes before he died, the sister of the ward in Altnagelvin stuck her head round the door and said "[GRO-B] can I speak to you please?" She didn't come in to the room all the time we were there. Mammy left the room and went to speak to her. My sister [GRO-B] a family friend [GRO-B] and I were in the room. Within a couple of minutes, we knew daddy was going to die so we asked [GRO-B] to run and get Mammy. Mammy literally made it back into the room just in time. It would have been awful if she had missed it as she had been by his side constantly.

ANONYMOUS

30. The reason the sister wanted to talk to her was to let her know that Daddy had to be buried in a closed leaded coffin and we would only be able to see him for one hour after his passing, which was an awful thing to find out a minute or so before he died. She could have told us this at any point in the five days before. I don't know but you would have expected more compassion in such a situation. We only had one final hour to spend with our daddy after he died and this was very distressing for us.
31. We had to quickly send for the rest of the family, my two brothers, my younger sister, [GRO-B] and my daughter, [GRO-B] I remember two strange women who were friends of my daddy's sister coming in to the room during that hour. I was really annoyed at this intrusion. We were denied the opportunity to have the traditional Irish wake with the body at home for a period in an open coffin to allow friends and loved ones to pay their final respects.
32. I recall at some stage a priest friend came to say Mass with the family in the days before he died. He used daddy's bed as the altar. I found this very soothing and special. The [GRO-B], also said mass in his bedroom while he was at home in the weeks before his death. He received the Last Rites a number of times over those terrible weeks.
33. I do remember though the transformation in his face just immediately after he died. His face was translucent, there were no wrinkles whereas before it had been contorted with pain.
34. When he passed away, liver failure was written as the cause of death on his death certificate. [GRO-B] who had been his life-long GP phoned Mammy and asked her to let him write the death certificate. I don't know why. I think there is also HIV-related illness and Hepatitis written on it.

ANONYMOUS

35. We told people that Daddy died from liver failure as we didn't want people to know the real reason. During the period when his body was at home, someone asked me why the coffin was closed and I didn't know what to say so I think I said it was because he was a haemophiliac. As mentioned earlier, in Ireland, it is normal to have a three-day wake with the coffin open.
36. After he passed away, Mammy was completely devastated as we all were. I often feel that we all withdrew from one another and didn't talk about what had happened to any extent. But Mammy was completely heartbroken and has never really got over Daddy's death. In my case, I just learned to deal with it.
37. I think that she never talked about it and that has meant it has been harder to deal with it. I once tried to encourage her to talk about it but she responded by saying: 'That if I opened the floodgates, they'd never close.' I think this captures her distress and devastation and also the isolation of her grief. I do recall – and it's with regret – that our youngest brother who was only fifteen at the time was in a way left to fend for himself and deal with his own grief as Mammy, in fact all of us initially, were consumed with our own.
38. I was with Mammy a lot for the first couple of weeks after Daddy died and she went missing one day and I asked her "where did you go?" She had driven to Altnagelvin Hospital and to the area all around it in a panic just looking for him. She thought she may get some kind of feeling of closeness. It was terrible. Just terrible. With the passage of time she has just learned how to cope with it, but she's always had a sadness about her since and was deprived of the opportunity to enjoy as full a life as she could have had.
39. Losing Daddy was obviously terrible for me as we all adored him. We looked up to him so much. He was so inspirational. I think the hardest thing was not telling anyone or talking to each other about it. We didn't

ANONYMOUS

tell anybody what had happened to him. Then, eventually, I told my husband, who was the first person I told. There was the loss, but then there's anger too. There's nothing you can really do about it though.

40. He was also a loss to the whole community. Everyone in [GRO-B] knew Daddy because he was so good and kind to people. If people were troubled he would go and help them and his reputation meant he was always going to someone's house to help with a problem or provide support.
41. He was a successful antique dealer and auctioneer until about 1974. So much so that he was head-hunted by [GRO-B]. He was to represent them in Europe and was offered fantastic money for the time but turned it down. Financial reward did not hold any appeal to him. Family meant more.
42. Later on, he had to close his [GRO-B] at the height of the Troubles when as many as six car bombs went off beside our home. Before that however, I remember one day we came home from school and there was this big mahogany table in the antique shop with beautiful wooden toys all over the table. We were all allowed to play with them and we couldn't wait to come back from school the next day to do so again. But when we arrived at the shop they had disappeared. We found out in later years, he had brought them up to the local children's home, [GRO-B], for the children there to play with.
43. There was also a time one Christmas when he took our Festive turkey to another family. He said they had nothing, no food, no presents, no hope. My Daddy, through his kindness brought them hope that day. When you were in his presence, you knew you were in the presence of someone wonderful. The fact that he owned an [GRO-B] cherishing old, often discarded items was typical of his nature. He spent his life cherishing people he met, showing an awareness of their history and recognising their humanity. That is why I said before that

ANONYMOUS

when he died, it was a huge loss to the community, as well as the family.

44. After closing the shop, he went back to university and trained as a social worker which is what he did after that. Despite his own suffering, he wanted to help those less fortunate than himself and throughout this, his final career, he worked tirelessly to improve the lives of those in his care. I recall one of his work colleagues saying; "Your Daddy never gives up; nothing is impossible." However, he left employment within months of his diagnosis and Mammy claims he was ostracised and forced to leave his job as a result of it. Financially, I would say it was quite a struggle after Daddy had to give up work. Mammy would have received only a small pension, as Daddy was self-employed both as an auctioneer and social worker.

45. I don't think Daddy had life insurance and so I don't actually know how Mammy paid for the funeral.

46. I don't remember Daddy having any problems with dentists but he would always have gone to the hospital because of the haemophilia.

Section 6. Treatment/Care/Support

47. As I said, I don't really believe that Daddy was offered any treatment apart from blood transfusions. It was just that there were not many options available.

48. No member of the family was offered any psychological counselling either at the time of his diagnosis or during his hospitalisation or after he passed away.

Section 7. Financial Assistance

49. Mammy quite recently got some support from the Skipton Fund. She found out about it because my cousin saw Dr [GRO-B] from the Haemophilia department at [GRO-B] [GRO-B] who mentioned it and my cousin's husband told Mammy. Even with that, Mammy was annoyed because Dr [GRO-B] was disclosing that information to someone when she hadn't even spoken to anyone about it herself. This was only about five years ago.

50. I think she got £70,000 from the Skipton Fund – a £20,000 Stage 1 Payment and then £50,000 in top up payments. She kept none of that money for herself and split it between the five of us. She also got something from the Terrence Higgins Trust years before that. I am not aware if she contacted or heard anything from the Macfarlane Trust regarding the HIV.

51. I remember Dr [GRO-B] once told Mammy that she could apply for a holiday and Mammy was outraged. The last thing she wanted was a holiday. This was shortly after daddy's death.

52. She also asked one of the funds for money for something on a particular occasion and it was turned down but I can't remember any more details.

Section 8. Other Issues

53. I suppose I am very angry with people like Kenneth Clarke who I believe was health minister at the time and the government who covered it up and knew that the blood products coming from America were contaminated yet still allowed it to go on. US drug users and other high- risk groups had peddled their infected blood for measly sums. Pharmaceutical companies driven by greed, profits and immorality sold

ANONYMOUS

their deadly contaminated stock to hospitals. I am angry about the families that it has torn apart for no reason.

54. It is great that the treatment is available now but Factor VIII, hailed the 'wonder drug' ended up killing so many. We lost our Daddy at 54, both our family and a whole community, lost a great man. The compensation is irrelevant as you've lost a person that you love. Thank God he saw his first grandchild but it's very painful that he's not here to enjoy his other grand-children. It is such a tragedy that he's missed all the special family occasions, birthdays, First Holy Communions and so on. We're fortunate that the legacy he left us has been enormous but grief never really goes away, it just changes.

55. It has shaken my faith in the NHS and pharmaceutical companies, of course. I was also angry with people for a long time. People like the funeral undertakers, and the women in the hospital who were there in our last hour with Daddy, so I guess I was just angry in general. I think Rock Hudson was the only famous person anyone knew about who had died of AIDS at that time. It was very scary as nobody knew what was going to happen. There was no remedial treatment and diagnosis was effectively a death sentence.

56. I have had two blood transfusions in my life now and that is also scary. I used to joke that I would get Mad Cow disease or something as a defence mechanism but I really did worry I might contract AIDS. Fortunately, I am fine.

57. Finally, an abiding memory I have of my father is a conversation just prior to his death. One day, as I sat at his bedside, he asked me to help him up. I was not sure what he wanted, or if I should, because he had not been out of the bed for many weeks. I helped him walk the few unsteady steps towards the large mahogany desk in the corner of his bedroom. As we walked across the room, I recalled a fleeting memory

ANONYMOUS

of the two of us standing in this very spot as he showed me an old Victorian brooch inscribed with the name **GRO-B** on it.

58. 'My grandmother was called **GRO-B**, he had said 'maybe one day when you have a little girl, you will call her **GRO-B**. It is a **GRO-B** word which means **GRO-B** and it is my favourite name.'

59. When we got to his desk, he opened the top drawer and took out some photos. Black and white photos of his wedding, his wife, his children, his parents and his brothers and sisters were carefully placed into little piles. Some later coloured photos of his children as they grew had their own little pile. I held my finger in place as he tied them together with a fine black thread into little bundles and returned them to the top drawer. He didn't say a word, he just slowly and carefully tended to those little bundles until his task was complete.

60. I named my first daughter **GRO-B**. She is my princess. He is still my king.

Statement of Truth

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

Signed

GRO-B

Dated 22nd January 2020