ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN3777001
Dated: 7.10.19

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 23 August 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1962 and my address is known to the Inquiry. I was born in Northern Ireland, the oldest child of GRO-B and GRO-B I have two younger sisters and two younger brothers. I trained as a nurse in Northern Ireland, and now work as a director of a medical device training company in England, where I live with my husband.

2. I intend to speak about my father GRO-B: F, who had haemophilia. He contracted Hepatitis C and HIV from contaminated cryoprecipitate and Factor VIII products. He later developed AIDS and died on GRO-B GRO-B 1987. I intend to speak about the nature of his illnesses, how the illnesses affected him and our family, the treatment he received and the impact it had on him and our lives together.

3. I confirm that I am not legally represented and that I wish to claim anonymity. The reason for this is that my mother still lives in the family home and two of my sisters and their families reside close by and what I am about to reveal has been, and remains a closely guarded family secret.

Section 2. How Affected

4. Daddy had severe haemophilia A. My family lived in GRO-B, and when Daddy experienced bleeds he was treated locally at GRO-B Hospital. He also attended the haemophilia centre at the GRO-B Hospital in GRO-B under the care of Dr Elizabeth Mayne. At one point, when our family were on holiday in around 1974 or 1975, he was also treated for a bleed at Swansea Hospital.

5. Originally, Daddy was treated with cryoprecipitate, which required him to spend long periods of time in hospital. Then at some point he began to be treated with Factor VIII.

6. We were told the Factor VIII was a wonder drug, and that it would change Daddy's life, which it did: it made life so much easier. But it also foreshortened his life considerably. We were never told of the risk of infection from Factor VIII at any time.

7. As far as I am aware, Daddy never received any blood transfusions. He was not an intravenous drug user and did not have any tattoos, and he was totally devoted to my mother. The only possible source of the Hepatitis C and HIV infections that he developed was the blood products he received.

8. The first infection I recall was around the end of 1972, when Daddy contracted non-A-non-B Hepatitis, or what we now call Hepatitis C. This first bout of hepatitis must have been from cryoprecipitate, because of

the timing, so it means he was given infected blood products prior to receiving Factor VIII.

9. When he was diagnosed with hepatitis Daddy was moved from GRO-B Hospital, where he was normally treated, to GRO-B GRO-B Hospital, as there was an infectious diseases facility there. His condition must have been serious as I recall Mammy came home and said to me, "Your daddy's dying, you need to take care of your brothers and sisters."

10. Daddy was isolated in a single room, and we were not allowed onto the ward. Every now and then, we would get taken through another ward out onto a balcony so that we could wave at him in through the window of his room.

11. From then on, Daddy had repeated bouts of Hepatitis C. Our kitchen at home was painted yellow, and I remember Mammy sitting in the kitchen looking at Daddy, and saying "Are you yellow because of the hepatitis, or are you yellow because you're reflecting the walls?"

12. Daddy was informed that he was HIV positive in early 1985. A short time earlier he had attended a meeting at the haemophilia centre in GRO-B and they had told him that there was a risk that he might have been exposed to HIV. Then he received a letter from Dr Elizabeth Mayne in GRO-B confirming his HIV status, which he showed to me. I had begun my training as a nurse by this time so I understood the implications.

13. I decided not to speak about the letter with any of my siblings. It was something Daddy shared with me, and I assumed he would share it with the others at the right time. My youngest brother was only 13.

14. It was not right that Daddy was informed via letter. Something should have been done face to face, that is right thing to do when dealing with something that is ultimately going to kill you. Even though there was the earlier meeting, can you imagine the shock of receiving this news

through the post, bearing in mind what a diagnosis of HIV meant in those days.

15. I do not know if Daddy was given any information about how to manage HIV. Our family was not given any information about cross-infection, in relation to HIV or Hepatitis C. For example, all of our toothbrushes continued to sit in the same cup together and we shared the same towels.

Section 3. Other Infections

16. I do not believe that Daddy received any infections from blood products other than Hepatitis C and HIV. Nor were the blood products directly responsible for any other illnesses that he subsequently contracted.

Section 4. Consent

17. I do not believe that Daddy was the subject of treatment without his knowledge but at the same time I am sure that he was never appraised of any risks associated with the use of Factor VIII. I also believe that he consented to the test for HIV in 1985. However, I do not believe that he consented to earlier tests or was aware of why or for what reason these tests were being conducted. How else could they tell when he seroconverted if he had not previously been tested? I believe that he was not denied any form of treatment that was available at the time.

Section 5. Impact

18. Daddy was a very religious man, but his illnesses did not shake his faith.

19. Daddy did not have any problems receiving dental treatment, he was treated in GRO-B. He also had a wonderful GP, GRO-B, who often treated him at home.

20. As far as I am aware Daddy never received any specific treatment for Hepatitis C or HIV, he was just cared for in hospital when it was needed. As I've mentioned, I do not think it was the case that there an available treatment that he was not offered. He would probably have been considered too far down the line to try a clinical trial or anything like that.

21. Following Daddy's first bout of Hepatitis C, there was no change in attitude from the hospital staff in Derry toward his treatment. In the later years I actually worked on the ward he was regularly admitted to, and I would just be told to get a single room ready for someone with hepatitis. On the door of the room there would be a sign, saying something like 'Infectious Protocol', but nothing on his chart. In my experience, someone being treated for haemophilia would not be placed in single room, but that was normal practice for treating an infectious disease.

22. In his final four years, Daddy had to take a lot of time off work when he was receiving treatment for the recurring hepatitis. He would be very tired and would have extreme itchiness in his arms and legs, it drove him crazy. At this stage he was working as a social worker. When I was growing up, he owned and worked in an GRO-B, but when he was 40 he went back to university and retrained.

23. During 1985, Daddy became progressively more ill and eventually had to retire on medical grounds at the end of the year. By this time, I had moved to GRO-B to continue my nursing training.

24. Daddy was very strong and carried on, but physically became very frail. He often had thrush in his throat, which is common for people who are immunocompromised. He had a number of instances of Bell's Palsy and at one stage developed a claw hand, which the doctors said would not recover but did.

25. At one point there was a discussion at the hospital in GRO-B about Daddy having a liver transplant. Daddy was teetotal, he never touched

alcohol, so this was because of the repeated damage from the hepatitis hence the often yellow tinge to his skin. However, because of his haemophilia the operation carried a huge risk and might have killed him, so it did not go ahead.

26. I really noticed how ill Daddy was when we travelled to [redacted] together in early 1987. I came home later in the year in June, around a month before he died. He was in bed as he had just had a bleed. His stomach was very bloated because his liver and spleen were enlarged. I made him pavlova, which was his favourite thing, and joked that he would do anything for me to come and visit.

27. I returned to [redacted] after [redacted] but then around Daddy's birthday, which was [redacted] I was contacted by a nun who was my superior where I was working. She told me "Your father's ill, he's been rushed to [redacted] you need to go home." I spent the next few weeks with Daddy at the hospital in [redacted]. For some unknown reason I always configure it as 6 weeks, albeit the timeline doesn't fit. I think the sheer exhaustion I felt at the time just caused the confusion. The family helped with his needs such as feeding. Someone was present around the clock. However, he did not want to die in hospital, so eventually he came home, around one week before he died.

28. I was told by my employer in [redacted] that I needed to return and finish my training, which I did. Four days later however I got a call and was told that Daddy had been taken back to the hospital in Derry.

29. I had to nurse Daddy at the hospital in Derry that final week, and what he and our family experienced shattered our view of the NHS. The staff simply avoided him because he was an AIDs patient.

30. His treatment in [redacted] in the prior time period had been very different. I think because it was a haemophilia centre he was not the only person infected with Hepatitis C and HIV, so they did not treat him like a second-class citizen. That was how he was treated in Derry. The staff treated

him worse than they would treat a dog. He was left lying in soiled sheets when he was incontinent. I could do most things that were required nursing wise but that was the one part of his care that I did not do, as it was so personal. The staff just left him there even though we repeatedly asked them for help. They did not even apologise, they only said "we're busy." We were told later by a family friend, who was a social worker that the reason they avoided coming into Daddy's room was that they were upset that he was dying!

31. Daddy was in a lot of pain, and I said to the staff he needed pain relief. Eventually, a doctor came and spoke to Mammy and me. The doctor said, "If we do give him pain relief, you know what will happen". I said, "I don't want him to die in pain." The doctor repeated, "You know what will happen", and I replied "I'm aware, but I don't want him to die in pain."

32. We were referring to the fact that morphine depresses breathing, which meant that Daddy could die if it was given to him. But my overriding concern and that of my mother, was Daddy's pain. In the end, they gave him the pain relief, and he survived for two more days, he was that strong. That conversation was pretty much the only communication I had with a doctor in Daddy's last week. The standard of care offered to what was clearly a dying man was abysmal.

33. In Daddy's final moments we did not contact the staff, we wanted to let him die in peace. Afterward, we had to go and inform the staff, no one came to us. We were moved out of the room, and someone came in to certify the death.

34. Just before Daddy died, Mammy was told by the staff that when it happened he would be taken away and we would not see him again, there would be a closed coffin. I was not aware of this prior to the conversation, I did not know about any of the procedures.

35. We had a wake in the house, and the tradition was to have the coffin open for final respects to be paid by friends and family. My father was

well known and respected in the local community and had been a leading figure in church circles. The fact that Daddy's was closed raised questions, which none of us answered. Daddy was buried, and I think burial rather than cremation might have been allowed it was only 1987. I understand the practice for AIDS patients changed later.

36. We were charged by the undertakers for embalmment, but I am not exactly sure that it happened. The undertakers would have been aware of what was on the death certificate, which said 'non-A non-B Hepatitis' and 'liver failure'. It definitely did not say HIV or AIDS. I brought the death certificate to the registry, so I was very aware of what was on it.

37. We did not tell anyone about Daddy having HIV because of the stigma. It was associated with drug use and homosexuality. We were a very private family and it was a very private family matter. It was no one's business but ours, so we did not talk about it, even amongst ourselves. It is only since the Inquiry that we as a family are sitting down and talking about it – 32 years later. I think that alone indicates the extent of the impact on our immediate family as a whole.

38. Because we did not tell anyone about the HCV or HIV we were not ostracised socially. I was able to continue with my education, I think because I was able to put it out of my mind sometimes. I was aware of how ill Daddy was but part of me probably pretended that it was not going to affect him and everything would be ok.

39. I think because I was away from home it was maybe easier on me than it was on my sisters. At one point, GRO-B came to do a course in GRO-B. I said to her, "You do realise Daddy's dying?" She refused to believe me.

40. I never gave my mother credit for how strong she was, because at the time I believed Daddy was the strong one. She carried the family – ran the house, had the children well turned out – even though her heart was breaking because her husband was dying. I know that his death emotionally shattered my mother but she kept going for the rest of us.

Section 6. Treatment/Care/Support

41. Before his final week in hospital in Derry, I do not believe Daddy faced any difficulties or obstacles in obtaining treatment or care. During that week, however, he was deprived of appropriate, even basic care because he was suffering from AIDS and the staff were clearly afraid.

42. No one in our family was offered counselling or psychological support during Daddy's illnesses or after his death.

Section 7. Financial Assistance

43. Mammy received some money from the Macfarlane Trust. I believe they told her it was a one-off payment, and that would be it. I do not know how much she was given, or how she came to find out about the Trust. I am not aware of any conditions other than the fact it would be a one-off and she could not go back to them.

Section 8. Other Issues

44. I was never offered a test for Hepatitis C or HIV in connection with Daddy nor were the rest of the family as far as I am aware. It was only when I received needlestick injuries at work that I was tested. I am in the clear.

45. I feel that because it was known what blood products could do that what was done to Daddy was criminal. If he had been aware of the risks of Factor VIII then, because he had a wife and five children, I think he would have opted not to use the treatment.

46. I have had the Consent Form explained to me and am happy to sign it now on the basis it will only be submitted along with my signed statement.

Statement of Truth

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

Signed GRO-B

Dated 7.10.19