V18G0285

Witness Name: GRO-B
Statement No.: WITN2240001
Exhibits: Nil
Dated: 20/11/2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 November 2018.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B of GRO-B 1955. My address is known to the Inquiry. I am married to my husband GRO-B and I do not work. I intend to speak about my son's GRO-B: S1 and GRO-B: S2 In particular, the nature of their illness, how the illness affected them, the treatment received and the impact it had on them and our lives together.

Section 2. How Affected

2. On GRO-B 1975 I had twin sons. This was S1 and S2 They were identical twins.

3. My sons both suffered from haemophilia A and this was severe. Both of my sons were severe. But a lot of the sums required because of the haemophilia was factor 8.

4. It was when my sons were about a-year-old that it was discovered that they had Haemophilia. Until they were three years old, in around 1978, they were treated at Yorkhill. Before we started on treatment we would be up about two days per week to Yorkhill. After the boys turned about 3 years old we began home treatment. This will treatment was twice a week was done by injection. Either I or their dad would have administered their treatment at home.

5. I believe it was when my children were 10 years old that we were informed that they were infected with hepatitis C and HIV. I believe that we were informed of the HIV first. There was an issue with the blood count down with S1 My sons received regular tests on blood because of them being haemophiliacs.

6. I recall when S1 went on a drug called AZT. I believe this would have been around 1989. I recall that we have on holiday to the Isle of Wight and we had to stop constantly as he was unwell, and had to vomit. This was done in liquid form. We were concerned as the doctor's did not seem to know what they were doing when dealing with children with HIV in terms of medication.

7. My husband would be better placed to know exact dates but I believe, when my sons were 11 or 12 they were overdosed on AZT.

8. I believe it was a pharmacist within Yorkhill Hospital who informed us that the boys had been getting too much of the AZT treatment.

9. The symptoms started about when they were 10 years old. They started losing weight and I recall his hair falling out. S1 had mouth ulcers and he could not eat properly.

10. We waited until they were about 12 to tell them about their infection. I believe that we told my two daughters many years later. They are GRO-B who is now 47 and GRO-B who is now 37. Both of us were told at the same time. We tried to protect the girls from knowing about their brothers' diagnosis.

11. There were times when the boys could be alright and then suddenly would have symptoms again for days, in the early days of them having HIV.

12. The person at Yorkhill who often dealt with our sons was the consultant, Dr Willoughby, and he fled the country before all this came out. I believe he knew something was wrong with factor that they were being given and that is why he fled.

13. Both my sons had hepatitis A when they were five years old. I believe that this was born blood products as well. It was just my sons there were infected with hepatitis A, but I do not think anyone else in the family had to get tested.

14. I think it would have been 1990 when we discovered that S1 s HIV had developed into AIDS. It was just as we got back from that holiday on the Isle of Wight that I previously stated within this statement. We were called in to see a consultant called Brenda Gibson at Yorkhill. I believe that she is a professor now.

15. In terms of symptoms I recall that he had a lot of chest infections. He was on inhaler. I am also aware that he had a lung infection called Numacystitis and that could have killed him. He would also have a lot of headaches. I wondered how he was still alive will all that he was going through.

16. My son's suffered severely from Haemophilia A.

17. My son's received Factor 8 as treatment for their haemophilia.

18. My son's were treated at Yorkhill Hospital by Dr Willoughby and a Dr Gibson.

19. My son's received treatment throughout their life, at least twice per week. They had to go to Yorkhill from when they were diagnosed until they started receiving home treatment.

20. When S1 was diagnosed with HIV I do not think we were given any advice

Section 3. Other Infections

21. My son's were infected with HIV and Hepatits C. Their HIV later developed into AIDS. I am unaware of any other infections that can be related to blood products.

Section 4. Consent

22. In terms of a testing done on my sons I believe that they were tested every time they went to hospital to check things like their iron levels. I never knew what they were testing for. I do not believe that adequate information was given at this point. You just trust doctors and don't realise what they're doing. I am unaware for certain if they would have known that he had hepatitis C or HIV prior to when they told us.

23. I believe that both of our boys may have been tested prior to us being told, for HIV or Hepatitis C. I do not have any evidence of this.

Section 5. Impact

24. I recall that I had to take S2 to hospital because he had a bump on his head. This would have been Yorkhill but I am not sure when. He was told he could not bring his own pyjamas and I recall that the TV and remote were covered in cling film. I was infuriated by this and ripped off all of the cling film. I do not think they had as clue how to deal with us once the boys were diagnosed as having Hepatitis C. These consultants are all supposed to know more than us, but I am not convinced that they did.

25. There was no advice given about how to manage either infection. The doctors and medical staff just seemed to be keeping their distance from us.

26. In terms of when the boys were diagnosed with Hepatitis C, I believe it was a doctor Hann who told us this. This would have been after we were told that boys had HIV. He was the sort of person who smiles nervously when he gives bad news. He said that he just wanted to let us know that the boys had Hepatitis too and he made an odd comment along the lines of "but you know that already didn't you". We did not know prior to this. I think they would have been 12 or 13 when we were told this. I do not believe that any advice was given about the hepatitis C and managing the infection other than being told that we should not share toothbrushes.

27. I believe it was in 1985 we were informed of the HIV diagnosis as I said. I believe it was in 1988 or 1989 that we were told that S1 s HIV had developed into AIDS. I recall that it was Dr Gibson that told us about S1 having AIDS. S1 passed in 1992.

28. The HIV and Hepatitis C ravaged both of my son's bodies, and caused them to be physically weak, but they were troopers with getting to school throughout their illness. As I have stated, S1 passed away as a result of AIDS.

29. HIV ravaged S1 body. He never reached puberty and this also stunted his growth. He and his brother had been identical, but were not identical by the time of S1 s passing. Doctors never made us feel welcome and never really seemed to understand what was going on. They treated us like our boys had an infectious disease that could spread to everyone.

30. We would always have to fight against hospital from when S1 was diagnosed.. We made a great friend in one of the nurses that treated S1 Her name was Chris Murphy. She was very good with him at Yorkhill. She was great with him. He hated hospitals because of how he would be poked and prodded. She made it that little bit easier when he had to go to hospital.

31. S1 died on GRO-B 1992. He was just 17. He had just got his first car, and passed his driving test. He was so proud of it. You'd see him sitting behind the wheel and he looked so small.

32. S2 went off the rails when his brother died. He was punching and headbutting walls. I am unsure if this had any effect on his school-work at the time as he was going through his own illness.

33. It was when S1 passed that S2 started showing signs of illness. He could not put one foot in front of the other. Thankfully for him new drugs came out. These new drugs meant that S2 is still alive, although he does have AIDS. He is still very thin but he has a daughter now. We call her my miracle granddaughter. They live on

the GRO-B Hepatitis C medication nearly killed S2 They made him so unwell but he persevered. He got through the round of treatment and I'm sure this was a year that was on this. This was probably interferon but I am unsure. I am unsure of exactly when he would have got this treatment. I do not think that S1 got this treatment, as he may have been too unwell for this.

34. There was a little team of us at the hospital, with children who had been infected by contaminated blood. It was as if there were kids funerals all one after the other. We used to think that S2 would be next.

35. S2 was diagnosed with AIDS 3 years after S1 as far as I recall. We thought he was a goner, but there were new treatments. Up until recently he was on 8 pills per day. These pills made him aggressive. Now he is on a new type of medication where he only has to take one per day and he is no longer aggressive. He does have joint pain. I can hardly believe what he's gone through.

36. S1 coped terribly mentally with the treatments he had but he was little trooper. I do not know how he manage to get to school through this time.

37. I recall that Prof Parry Jones from Yorkhill Hospital offered for counselling at some stage. I do not recall exactly when this happened. This was counselling for both of us as parents. We actually did find this quite helpful.

38. I recall that after S1 passed two doctors came to see me. I do recall that they offered a post-mortem and I initially told them no. Thereafter myself and my husband said we did want a post-mortem just in case anything happened with S2 in case it could help him.

39. My husband said that six months later the same doctors came to him and said that S1 had measles on the brain and that is what killed him. We thought it was something else in relation to his infection but if he had been diagnosed he couldn't possibly save them. One of the doctors maybe James McMenemy.

40. S1 was admitted in 1992 shortly before he passed away. I believe it was around 14 August and he was there until his death. Around 21 August he started fitting. It was terrible. I recall that the offered to take him off his medication. This was in Ruchhill hospital in the infectious disease ward. He was in with all the HIV and AIDS patients and a lot of them are drug addicts. It was certainly a lively ward.

41. I recall that S1s last meal was fish and chips and this was three days after being admitted. We parked his car in sight of the window of his room so he could see it. As he was unwell he was sort of out of it but he did not lose sense of humour. My husband and I slept in hospital and took turns.

42. I recall that in the lead up to S1s death he was in and out of hospital frequently as an outpatient. I recall one morning he woke up and shouted for me. I do not recall when exactly this happened. He could not move and his left side was paralysed. I had to bundle him into a car and take him to Ruchill. I recall thinking that it was only a couple of months before that he had been playing golf in GRO-B

43. S1 was helped by a homoeopathic doctor, Dr Riley, just before he passed in Ruchill. I believe it is because of Dr Riley that S1 was able to pass peacefully. I'm not sure what he used but it was some sort of potions and lotions.

44. I recall that when S1 was at school and he would be running home because he knew he was going to have violent diarrhoea. He said he struggled to cope. He would not let me stop him going to school. He was a trooper. The year before he died he was in the play Oliver. The school was devastated and we would have people turning up with cards all the time. He was certainly a well-loved boy.

45. Both of my children developed AIDS, but S2 developed it later than S1 and therefore was able to receive treatment which has prolonged his life.

46. The AZT drug that they were put on when they were diagnosed with HIV was taken three times daily. Just from the smell I could tell that it probably tasted like Domestos. It was disgusting. I believe that they could not give them this in pill form because of the need to dilute it.

47. I believe the boys were given all treatments that they could have had at that that time. Things were different for S2 as his AIDS developed later.

48. I am unaware if there were any treatments not given to my sons which could have been.

49. As I have said, the AZT drug was disgusting and did cause both boys to be unwell. Symptoms included the likes of vomiting.

50. I recall one stage that I had to take S1 to the dental hospital in Glasgow. This would have been when he was 10 or 11 years old. This would have been shortly after he was diagnosed. His mouth was caving in with cavities. I do not recall the name of any consultant I saw at that time, nor do I recall the eventual outcome of this. S1 and S2 had no difficulty getting dental treatment as they were able to get this at Yorkhill.

51. We would only go on nights out with people who were in the same situation as us. We never told anyone. Even today people still do not know what happened.

52. Our family life was hell. My husband and I almost broke up. At one stage he left me for two nights. Even now I would say that we are not fine but that we are getting there. We have not had a life.

53. Our social life changed completely because of our boys' diagnoses. We used to have a caravan at GRO-B As you do when you're on holiday you get to know people that ended up getting our guard up. This was because we were wary of people finding out about the boys' condition.

54. When S1 died we went to empty the caravan, before getting rid of it. I remember that some people we had known at the caravan site came over and asked what was going on. They would not believe it when we told them that S1 had died.

55. We had a very different social life before I was diagnosed. We would have dinner parties with friends.

56. While S1 and S2 were ill I did not have time to work. I spent a lot of time looking after S1 and S2 After S1 passed I spent five years working as a phlebotomist. After that I looked after our grandchildren for about 10 years. One of our grandchildren is S2s daughter GRO-B who is five now and we still call her a miracle baby. GRO-B has two boys, GRO-B who is 15 and GRO-B who is 12. GRO-B has one boy and a girl. GRO-B six and GRO-B is two. GRO-B suffers from haemophilia. GRO-B suffers very severely from his haemophilia. I recall that he had a brain scan on the day he was born. His veins are rubbish so he has a little port in his side and my daughter has to give him his treatment every two days.

57. My husband was a director of an electrical company until last year. He was a manager in a similar business during the boys' illness.

58. In terms of this stigma we felt like we were hiding a dirty secret.

59. In terms of medical records we do have some, but we are aware of the procurator fiscal asking that our son's medical records be destroyed. I do not recall how we found this out. My husband contacted Dr Emma Thomson at Gartnavel Hospital who got him some medical records and he will be able to speak that when he gives a statement I feel a lot of things were kept from us.

60. We were a lovely family before what happened. We shielded our daughters from a lot of it. It was horrendous at the time and it has been horrible re-living it again.

61. This has all ruined our family. It has utterly destroyed our family. We will never be a proper family ever again. We keep going because we have to keep going. No one's ever said anything about who was to blame. I feel guilty because they felt like I was taking a little box of death when I was taking his home treatments and I feel a terrible sense of guilt about this now.

62. In terms of S1 and S2s sisters GRO-B moved out to go to University in Glasgow around the time of S1 starting to be more ill. I think this would have been in the very early 90s. GRO-B was still in primary school at the time. GRO-Bs little boy has haemophilia so she knows the danger. Her son is treated every two days. I think what happened to her brothers does make her worry.

Section 6. Treatment/Care/Support

63. The children were offered counselling. This was both S1 and S2 I recall seeing them coming out of this laughing and having a

giggle. I do not believe counselling would have been beneficial for our daughters. We kept this from them. With the boys I think they were too young. The place where the received counselling was a place for kids with mental problems.

64. My husband GRO-B haemophilia group. I do not know the name of this. We would have secret meetings in old folks homes. There was a support group and was organised with the social worker, Christina Leach.

Section 7. Financial Assistance

65. I am unsure if we got any financial assistance from the Skipton fund or Caxton as my husband would have dealt with this. I recall that we got £1,000 towards S1 s funeral. We received a lump sum of £25,000 from the McFarlane Trust, maybe 15 years ago. I'm not entirely sure when exactly this happened. I thought it was rubbish. My husband dealt with any funding applications and or where ever they were any difficulties with this.

Section 8. Other Issues

66. I believe my husband may have given a statement to the Penrose Inquiry. I believe that the Inquiry was absolute rubbish. I can believe how long this will process has gone on. Our son has been dead for 20 years. It's ridiculous.. Penrose was a waste of time.

Statement of Truth

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

Signed GRO-B

Dated 26\1\19