Witness Name GRO-B

Statement No: WITN5694001

Exhibits: N/A

Dated: 7 May 2021

INFECTED BLOOD INQUIRY

STATEMENT OF GRO-B

Section 1: Introduction

1. I, GRO-B, make this Statement for the benefit and assistance of the Infected Blood Inquiry relating to the tragic circumstances of the death of my only son, GRO-B: S.

Section 2: How Affected

2. My son S was born on GRO-B 1977. Initially, he was incorrectly diagnosed at our local Hospital with mild Haemophilia A. It subsequently transpired after various bleeds occurred, that he was transferred to the care of St. Thomas's Hospital, London.

3. It subsequently therefore transpired that S had a Factor VIII deficiency level of less than 1% i.e. he was a person with severe Hemophilia A.

4. It should be noted that my daughter who was 13 years younger than S, is also a carrier of Haemophilia A. She is very conscious of the impact that Haemophilia can have upon a family arising from the experiences that occurred

in relation to the loss of her own brother. This has impacted upon her assessment of her options in the context of the next generation of her family.

5. Before S attended St. Thomas's Hospital, he had been in receipt of cryoprecipitate. Accordingly, after each bleed, he would receive treatment to alleviate the consequences of that bleed and acheive coagulation. At that time, no prophylaxis treatment was available and he attended the All Saints Hospital, Chatham. The treatment most of the time was effective but not brilliant.

6. Unfortunately, at aged 3, S developed a severe bleed into his knee, he was hospitalised and the Hospital Personnel were unable to control that particular bleed. Fortunately, a Medical Practitioner who had trained at St. Thomas's managed to achieve access or delivery of a bottle of Factor VIII concentrate which was sent down from St. Thomas's where that treatment of Factor VIII concentrate stopped the bleeding. As a result, both S and myself were dispatched in a taxi to St. Thomas's to ascertain what could be done to assist in relation to his onward treatment. St. Thomas's kept him in and that was the commencement of his care at that Hospital.

7. For the immediate period after that event, the care afforded in relation to S Hemophilia condition was combined care between our local Hospital and St. Thomas's.

8. Also, it should be noted that S was the first child to be admitted to St. Thomas's as in essence, a pediatric patient. Doctor Savidge, the then Director of The Hemophilia Centre indicated to myself that S could be transferred to Great Ormond Street but that he would prefer to keep him, and I acquiesced to that particular proposal as Doctor Savidge indicated that each boy would then transfer from the Pediatric Hospital or Centre to the Adult Hospital and it would be better if they attended that Hospital from the outset.

9. Although there was no Pediatric Team at the beginning of S care, eventually, Dr. Savidge built up a Pediatric type Team that looked after the children as S was joined by other child patients.

10. I had a very good relationship with Dr. Savidge in that he was the first Doctor who actually said to me as a mother "*what do you think?*" No Doctor had previously endeavored to engage for the purposes of ascertaining my views in relation to the treatment of my son. I felt that was an important development and change in circumstances.

1981 – 1984

11. During that time period, S was in and out of Hospital as there were various endeavors to repair the knee damage that had occurred. Those endeavors involved lots of orthopedic surgery, often necessitating 6-weeks hospitalsiation at a time and then a period of recuperation at home and back for further check-ups or indeed, in many instances, further operative intervention.

12. I now realize that each time S had his surgery, he had to have Factor VIII concentrate cover i.e. lots of Factor VIII concentrate. Unfortunately, S had had lesions on his knee which necessitated further operations.

13. During all these procedures, there was no discussion in connection with the risk of transmission of viral infections through receipt of imported commercial Factor VIII concentrate.

14. Also, there was no discussion in connection with commercial imported Factor VIII concentrates versus BPL/Elstree Factor VIII concentrate manufactured from plasma derived from U.K. donors.

15. My level of knowledge was limited, and I thought that this Factor VIII concentrate was a wonder drug as it had alleviated [redacted] bleeding consequences.

16. As a mother, for very understandable reasons, I would do anything that would alleviate or prevent my only child, my precious boy, being in pain.

17. As time progressed, I was trained to administer [redacted] Factor VIII concentrate. Also, I made the decision for [redacted] benefit to move his Hemophilia care away from the combined status of care with our local Hospital and solely to St. Thomas's.

18. This decision had one effect in that the local Hospital would not take the sharps or needles which I was required then to bring in a biscuit tin to St. Thomas's for safe disposal.

19. At that time, I did not consider it an imposition or difficulty to undertake the journey to St. Thomas's as [redacted] was achieving such excellent care that I felt at all times that it was worth getting on a train to provide that assistance and support to him.

Care after 1985

20. It should be noted that Dr. Savidge continued to look after [redacted] where his Haemophilia care was excellent. Also, as indicated, he had access to a HIV nurse. I recall another Doctor was involved in his care who may have been a HIV Consultant. As AZT became available on an unlicensed or trial basis, when [redacted] was aged 17 years, he commenced that particular treatment for his HIV condition.

School

21. As one would expect in the context of the hysteria that existed associated with HIV infection, I didn't tell S school of his HIV diagnosis. I must admit that I was too frightened to do so for the consequences that might occur to S

22. When S was aged 8 years old, I was summoned to the Headmaster's Office, to use that expression, and I was asked directly if S was HIV positive. I confirmed the situation, although it was not a comfortable disclosure to have to make. Every fear and trepidation that I expected could occur then materialized. The Headmaster indicated that he wished, having received that information, to write to every parent in the school and inform those parents (without identifying S by name) that there was a HIV positive child in the school. As S was the only child with Hemophilia in the school, it wouldn't take a genius to work out the identity of the child concerned. Accordingly, I went to a Solicitor who acted on my behalf and advanced a Court Application to achieve a High Court Order preventing the Headmaster disclosing that detail to every parent in S school.

23. Even Educational Authorities did not appear to have a willingness to treat S situation with the sensitivity that it deserved.

Senior School

24. Arising from my experiences, I didn't tell the school personnel of S HIV diagnosis. For understandable reasons and indeed arising from the reaction during the course of Junior School, I felt that it would be a retrograde step to make such a disclosure.

25. Fortunately, the school was a large school and it had a permanent School Nurse. I had a meeting with her, and I used what can only been termed as a coded disclosure method. I brought to the meeting a pair of white plastic gloves. I emphasized that if S needed Factor VIII concentrate, he could

administer it himself. I sought that the facility would be provided of her room but that if she needed to deal with him in any way, that she should use the plastic gloves. Her response was that she always used universal precaution procedures with every child. Although nothing was said, so nothing had to be noted on any school record, there was from the look of response that I received, a clear understanding between the two of us. Accordingly, S had no problems during the course of Second Level education.

26. Although, it might have been perceived that I would have slacked off in some respect in relation to S educational endeavor, the contrary was the situation. At every opportunity, I encouraged him to perform to the best of his ability to achieve educational qualifications or school exam results.

S

27. Eventually, the pressures and stresses of life took its toll upon S. One day I received a phone call from a lady in an Off-Licence who had S with her where she indicated that he was very poorly. She through the goodness of her heart had called an ambulance and accordingly, I drove to the local Hospital's A&E Department.

28. I found S in a trance, I don't know what had happened or what he had taken but I learned that he had taken drugs. Subseqeuntly he had informed me that he was so fed up with life that he did not know how to deal with life itself. Also he had been suffering from depression where it should be remembered that in October 1994, S was aged 17 years i.e. he did not have the experiences of life to be able to deal with the consequences that were occuring during his teenage years.

29. I believe that this episode was the beginning of the spiral of chest infections where those chest infections continued but each time after such an infection, S bounced back a little less. In essence, it was the beginning of the decline into his eventual demise.

30. At that time, I did not know that that type of situation was to occur and I sought as the mother with responsiblity for the care of my son that he would be transferred from our local Hospital, GRO-B Hospital, to St. Thomas's. I realised that that Hospital did not know his background nor indeed were they equipped to deal with his circumstances. An ambulance was dispatched from St. Thomas's and brought him up to that Hospital where the treatment in relation to his pneumonia or particular type of pneumonia commenced. Over the next 6 months, S started this process of recovery, further relapse, additional recovery and eventually he slid down the road to inevitable decline.

31 S passed from this life on GRO-B 1995. He was just aged 18 years.

Section 3: Other Infections

32. The range of health issues included the following: -

- Consistent and persistent chest infections which were eventually diagnosed as pneumocystis carinii (PCP). Accordingly, S was prescribed on a prophylactic basis Septin.
- Falling and plummeting CD4 counts where, S was always at risk of an AIDS defining illness.
- Bulging blue veins on S hand.
- Problems with peripheral neuropathy or nerve endings.
- Significant loss of weight.

Section 4: Consent

33. During the course of S care at St. Thomas's in the period of his lifetime, I never was informed until after his death that he had contracted Hepatitis C.

Section 5: Impact

S parents

34. I have no doubt that S situation contributed in large part to the breakup of the relationship between S father and myself. After S HIV diagnosis, S father could never become easily involved with S care. Always there was a reticence or withdrawal of effort that did not assist in our parental duties. GRO-B never did administer the Factor VIII concentrates; he never went to the Hospital. If S was hospitalized, he would visit very occasionally.

35. These situations and other similar situations created tensions and eventually, we drifted apart. My husband left us the day after S third birthday, saying he couldn't cope with the stress (this was even before we had the diagnosis of HIV) and chose not to have a great deal of contact afterwards.

36. I firmly believe that that relationship would not have broken up but for S healthcare and indeed health issues. Also, I know in my heart that my husband had been pushed to the background as S welfare at all times was the paramount consideration. It should be remembered that we were a young couple then aged 22 so we hadn't life's experiences nor indeed the supports necessary to be able to deal with the catastrophic impact of S potentially terminal diagnosis. In short, the maturity of life itself had not occurred to the extent that we were equipped to address these issues. Accordingly, it was an inevitability that that relationship would sunder.

My Life

37. I was twenty years old when S was born and thirty-eight when he died and my whole life during those years revolved around S and the double whammy of his Hemophilia and HIV.

38. During his short life, S spent many months in hospital, and I chose to always stay with him and help with his nursing care. I was unable to hold down a job and money was always tight. During those years, both S and I were dependent upon Income Support, Mobility Allowance and Carer's Allowance as we had no other Income coming into our home except an allowance of Maintenance from my former husband.

39. It was frustrating at times as, before I had my son, I was building a career in the food processing industry as a lab technician and attending college, studying for City and Guilds qualifications. I had hoped to continue with this at some point, but it proved impossible. I was in and out of Hospital, but his prophylaxis treatment ought to have delivered an improved quality of life and I would have intended to return to the workplace as is necessary to earn a livelihood. Yet I did not do so at that time as my focus moved from Hemophilia to dealing with the consequences of HIV infection.

40. When I was finally told of S HIV status in 1984, I made the decision to tell only my ex-husband and my sister; I was terrified of the stigma involved if it became general knowledge. I didn't even tell my parents. I recall so vividly the media campaigns to minimize risk of transmission of HIV. I can see the Grim Reaper with his scythe, the tombstones and I can recall very vividly the unnecessary hysteria created by that media campaign. My child, S, suffered the consequences of such a campaign and I am saying it not just as a mother of that child but as a Phlebotomist. I believe that that campaign was unnecessary, inappropriate and without consideration for the impact that it would cause to those children or indeed persons who were infected with HIV through receipt of contaminated blood products or otherwise.

41. I became aware that friends were suddenly making themselves scarce. The truth is that you know your friends at a time of difficulty. Several of my so-called friends dropped me due predominantly to the perception or fear that S as a Hemophiliac might have contracted HIV. At no time did I make such a disclosure but the fear of such a consequence was enough for a dropping to

occur. Such was the extent of hysteria that it was enough that somebody thought that your child could have contracted HIV from contaminated blood products to be dropped and for parents to drop that child from association with their children.

42. The following few years were extremely frightening, stressful and lonely. I didn't attempt to strike up new friendships because I was so wary of anyone guessing S condition. The strain of keeping up the appearance of normality was enormous, but necessary. The stress caused me to lose a lot of weight [I weighed less than seven stone] and I suffered greatly from dental abscesses. Our world became more and more insular. I still don't have any friends; that became a way of life.

43. Then, in 1988, I started a relationship with my now partner, GRO-B. We had known each other for some years previously and we became very close. He was marvelous with S and although concerned about the HIV, was very caring and supportive. He even visited the staff in the Hemophilia Dept at St. Thomas' to discuss S care; something S own father had never bothered to do.

44. Our daughter GRO-B was born in GRO-B 1990 and S was absolutely thrilled. For a little while we were all able to lead quite a normal family life, albeit with the dark cloud of S illness hanging over us; it was very difficult to get a poorly teenager and a baby to St. Thomas' in order to attend S increasingly frequent appointments. However, it quickly became obvious that S health was deteriorating rapidly, necessitating a move to a bungalow. This brought even more worry and stress as, once purchased, we were unable to obtain the previously promised grants as the local council had run out of funds. The following months were a complete nightmare; GRO-B, aged four, stayed with my sister while GRO-B lived on site in a tatty little caravan, desperately trying to complete the modernization of the bungalow and I stayed with S in hospital. Heartbreakingly, S was only able to spend three weeks with us there before he died.

45. My life fell to pieces after S died. There were anonymous phone calls and even a Christmas card, blaming me for S illness and death. There was no counselling available, not even for GRO-B, who missed her brother enormously. GRO-B was self-employed so unable to earn much during this time, we were in debt. Eventually the strain and loss became too much to bear and GRO-B and I separated. Thankfully we were reconciled some eighteen months later and have been together ever since, but it was a very painful time for all of us.

46. Also, financial necessity required that I reenter the workplace. Somewhat ironically, I obtained a position as a Phlebotomist with the NHS. It would appear that one of the major contributing factors to my achieving that position was my experience in dealing with S injections of Factor VIII concentrate i.e. I had both practical and theoretical knowledge.

47. Even now, somethings are too painful to put into words. I miss S more and more with each passing year.

Section 6: Treatment/Care/Support

Alternative Treatment Options

48. I recall that for a period of time S was in receipt of freeze-dried cryoprecipitate. I estimate that this was in or around S being aged 6 or 7 years, where he was able to take that treatment home and it would be administered by myself on a prophylaxis or preventative basis.

49. For the avoidance of any doubt, during the period 1981 and indeed up to 1985, no alternative options in terms of treatment that provided any additional safety

to [redacted] was offered to me. Also, no mention of risk of transmission of AIDS existed in the context of the provision of treatment on an ongoing basis to [redacted].

50. I consider myself to be a relatively informed parent who has an interest in her child's welfare and in or around [redacted] 7th birthday, I recall receiving a phone call from the Hospital to attend. I was aware that a lot of discussion in connection with AIDS existed.

51. When Dr. Savidge said that [redacted] was HIV positive, it came not as a shock but as an almost inevitable expectation considering the amount of talk or discussion that had occurred.

52. Dr. Savidge indicated that he was unsure as to how it was transmitted. I was advised not to cuddle [redacted] anymore and I received advice re: sharps and needles. We talked about cutlery, plates and safe systems in the context of [redacted] situation. Also, I was tested for HIV and fortuitously, I was HIV negative. I know that Dr. Savidge appeared upset on the day concerned as I suspect that he, like myself, did not wish to find himself in that situation.

53. After [redacted] HIV diagnosis, I made no alteration at all to the manner in which I treated my son, [redacted] The washing of his clothes was with my own washing. Admittedly, I was very careful when he had a bleed, but that was only common sense. My child was aged 7 years, so I wasn't going to treat him any differently nor was I going to make any further reason for upset for him. I solely wished to continue to assist him in whatever way I could and make his life as comfortable and as perfect as I was capable of achieving.

54. Yet, I do remember an incident at Guys Hospital where [redacted] was attending for dental treatment. Both the Dentist and the two Assistant Nurses approached the dental appointment in what I can only term to be astronaut gear with helmets attached. The appearance of such was that it caused [redacted] to have a wobble i.e. he became upset. Accordingly, the Dentist took off his suit as he realised it

was over the top and that S was only a little child and that the response was excessive.

Care from St. Thomas's

55. As set out above, the meeting in connection with S HIV diagnosis was a sad situation for all concerned. As I indicated, I had half guessed that such a devastating diagnosis would be delivered. I also noted that Dr. Savidge was quite upset. During the course of the many years that occurred where S was under St. Thomas's care, I always found that Dr. Savidge was at the end of the telephone if so required.

56. Yet he was generally away at conferences and otherwise, there was not a huge amount of support. The Hospital had a HIV nurse who was very approachable, but her role was to provide physical type assistance for physical type consequences in other words to address the immediate requirements of people who were seriously ill.

The Hemophilia Society

57. I recall support during the early years post S HIV diagnosis from David Watters, CEO of The Haemophilia Society. He helped me to try to get Social Welfare Allowances and Allowances for extra nutrition for S. My case was somewhat of a test case and I lodged the Appeal. Unfortunately, the Appeal was unsuccessful, and we did not manage to achieve the paltry payment necessary to provide additional nutritional requirements to S.

58. Accordingly, it was necessary to return to work which I indicated that I undertook in 1991.

Section 7: Financial Assistance

Circumstances in or around 1991

59. As indicated, I was living with my partner, we needed the money to survive and there were significant additional outgoings with S situation. Financial issues were tight as my partner was self-employed, once I set up a family unit with him, we lost our Carer's Allowances and accordingly, I commenced working 4 days per week.

60. After the HIV settlement was approved by the Courts, the monies from that settlement were rightly paid into Court. Consequently, we as a family did not have access to same for general costs to be discharged.

61. I recall that I received £1,000.00 which was termed to be for the stress of being S mother at a time of his HIV infection.

62. I cannot emphasise how difficult and how stressful and horrendous that period was in our lives. Not only were we dealing with the healthcare and health support issues that S required but we were trying to survive financially in the context of less income than previously existed and given that the grant for the bungalow did not work out.

McFarlane Trust

63. I received monthly payments from that Trust through The Haemophilia Society which were very much appreciated at the relevant times of financial need.

Skipton Fund

64. I received an interim payment some 7 years ago and a secretary who had been in St. Thomas's for many years indicated that I should make further application for the higher rate. There were problems in terms of achieving access to the

Medical Notes and when I did make the Application for the second payment, it was achieved. I find it strange that in the context of my own situation, that it took so long to achieve access to any payment from the Skipton Fund, that it took a secretary to point out that I should look for a further payment where the amounts involved were for the first payment £25,000.00 and for the second payment £50,000.00.

65. I used that particular payment for a medical requirement related to the stress of my own experiences.

Section 8: Other Issues

Reflections

66. Whether I am right or I am wrong, I firmly believe that the lack of support and care afforded to S during his teenage years when he was most vulnerable in psychological terms created a very tragic and unfortunate scenario. S did have available at St. Thomas's a Nurse Counsellor but he knew her from his time as a little boy and he viewed her more as a Nurse rather than a Counsellor or person to whom he could open up to. Accordingly, he had no-one and indeed, would not have felt appropriate to burden myself with any such private thoughts or issues.

67. If S had survived for a further year, which was very possible I believe if those events in terms of the drug use had not occurred, then he would have managed to achieve the life-saving effect or life-prolonging effect of proteus inhibitor or Triple Therapy treatment. It was unknown to myself in 1995 that at the end of that year, a Medical Conference in Vancouver would occur that disclosed the efficacy of HIV treatment options that then existed for the purpose of prolonging life itself. If my little boy, my only son, had managed to survive a few more months, then he could have achieved the benefit of those treatment options. I believe if his psychological profile had been appreciated, the necessary support required provided, then his chances of surviving would have existed.

The Death Certificate

68. The Death Certificate is incorrect in that it refers solely to cause of death as being pneumonia. Somewhat ironically, S was born the day after my Mum's birthday and died the day after my Dad's birthday which is a somewhat unusual coincidence.

Retrospective Perspective

69. I can't emphasise how difficult it was for me as a mother or a sole parent to tell S when he was aged 11 years old of his HIV status before he went into Second Level education. It transpired that S had known but he didn't want to disclose that information to myself as he was afraid of the repercussions. So he had suffered in silence unbeknownst to myself.

70. At one stage, there was a proposal that S would go to a special Boarding School where children with disabilities were trained in particular disciplines. I didn't accept that particular proposal and indeed I objected very strenuously to it where Dr. Savidge subsequently indicated that my perspective was correct.

71. The most difficult aspect of S situation was the constant worry or fear that disclosure of S situation would occur. I lived a complete lie to protect S from stigmatisation, ostracisation and indeed, the prospect of being abused due to his HIV status. I didn't even tell our G.P. and arranged that all of S care was undertaken at St. Thomas's Hospital. Also I didn't inform my own parents and the only persons who knew of S HIV status were S dad and my sister.

Post-Death Assistance

72. No counselling in terms of addressing in whatever manner was appropriate was available for either my daughter or myself in the circumstances surrounding S tragic passing. To this day, I avoid talking about it to people in work or

any stranger. I think about S every day. Also, I get cross in work when I consider the pain and suffering that S endured where others are less capable of receiving or enduring significantly lesser amounts of pain.

73. Looking back, I don't know how I got through it, it should be noted that even after S death it continued to have an effect. My partner and I split up for 18 months some 5 years after S died as I needed time and he let me work it out for myself or to get the space that I needed to work it out. We have been together for in the region of three decades now except for that break.

74. Also I don't have S grave to attend as I was told that S would have to be cremated in 1995.

75. S had died at our local Hospital under the care of a particular Respiratory Physician who attended both St. Thomas's and that Hospital. It had become increasingly difficult for S to travel to St. Thomas's and would prefer to go to GRO-B to see that particular Medical Practitioner to avoid the ardous journey.

S death

76. At the time of S death he had been a Third Level student. After S death, a class prize or award was made in S honour.

This Inquiry

77. I had recognised that S had died aged 18, this Inquiry dragged up the past and caused me to want it to be acknowledged that I had lost my son, I felt arising from the establishment of the Inquiry that I lost him for a second time. I had had at least 15 years of normality and I found that knowing yet again that his circumstances of HIV infection would be considered required the necessity

for me to have it acknowledged as to what happened. Also, that situation created an effect like a second bereavement.

78. Also, like many mothers of children with Haemophilia, I will go to my grave knowing that in all probability I administered the Factor VIII treatment that caused my son to contract HIV that resulted in his death. It is very hard to countenance that fact or catch it in language that immeliorates or reduces its full effect or impact. I know I administered a lethal injection to my son, although unwittingly, that caused him to suffer the consequences and ravages of HIV infection for the vast majority of his shortened lifespan.

Statement of Truth:

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

Dated the 7th day of May 2021

Signed: GRO-C

GRO-B