Witness Name: GRO-B
Statement No: WITN0597001
Exhibits: N/A
Dated: 15 April 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:

Section 1: Introduction

1. I GRO-B was born on GRO-B I am the widow of the late GRO-B: H who was born in GRO-B and moved to the UK when he was around GRO-B years old. We first met in college around 1980 and our relationship began shortly afterwards. We were married on GRO-B Sadly, six months later, on GRO-B he passed away at the young age of GRO-B H was a severe Haemophilia A, sufferer and regularly required blood transfusions to manage his condition.

2. The following statement was prepared without the benefit of my late husband's medical records as I received correspondence which confirmed that they were destroyed many years ago.

Section 2: How Affected

3. H attended Treloar's school in Hampshire, up until he was around 18 years old. As he was diagnosed with severe Haemophilia A, he received medication to manage his condition from the medical staff on site.

4. When he returned to live in London he would attend his GP practice in GRO-B GRO-B and GRO-B, where he collected his medication from and later saw GRO-B At this point he was generally self-administering Factor VIII, unless he suffered a particularly bad bleed, then he would attend hospital to receive the necessary treatment/transfusion.

5. H was tested and subsequently diagnosed with the HIV virus in/around 1986, so it is likely he received the contaminated factor VIII blood products from GRO-B hospital.

6. Following the diagnosis H was naturally devastated and distraught. When he was diagnosed we as a couple did not receive any professional advice or counselling.

7. I have serious concerns as to why there was a delay in providing a test and subsequent diagnosis. Such information would at the very least have enabled us to come to terms with what was to come and prepared us for the very difficult time ahead.

8. I believe H case is highly relevant to the issues that surrounded the knowledge that was available at the time, of the potential risks and the wrongful withholding of this information from recipients of the treatment.

9. During this era there was a very high risk of being infected with HIV from Factor VIII concentrates. Questions need to be asked regarding what alternatives existed during this period and why they were not being used. If alternatives were available why was H and others who were infected not afforded any choice in treatment?

10. At some point after the HIV diagnosis H was prescribed the drug AZT, although I cannot remember exactly when this was. During this time he experienced fungal infections on his feet, stomach upsets and diarrhoea, extreme tiredness and sweating at night. An entry in my diary states 'his stomach was still very queasy caused by his AZT tablets'.

11. H continued to have frequent transfusions and attended GRO-B hospital to ascertain his T cell count and assess his state of health. He was regularly weighed and was extremely underweight as a result of muscle wasting, relating back to his time

spent in a wheelchair as a child. To put this into perspective, he was six feet tall and generally weighed in the region of eight and a half stone.

12. Attending the hospital for his T cell count appointments was stressful for both of us. If they'd gone up we felt a glimmer of hope but we dreaded the news that next time they may drop again. H and I were very fearful regarding what the future may hold, especially when considering signs of physical deterioration such as severe skin conditions, emaciation, blindness etc. I remember watching a documentary with him about someone living/dying with HIV/AIDS and we were both extremely upset thinking this could be H predicament. However we still felt the need to educate ourselves and be realistic about the future.

13. H diagnosis had a profound effect on our lives especially at a very young age. Furthermore, this was the pre internet era so there was a lack of relevant information available, which made it extremely difficult to cope with.

14. The main concerns I had with regards to both the diagnosis of Haemophilia and HIV were his spontaneous bleeding, bruising, swelling of joints (knees and elbows) and the muscle wasting in his legs. Whilst at school in Hampshire H spent a lot of time in a wheelchair but due to being so determined to walk, he did not always use it and chose to use crutches or a walking stick instead. With regard to his HIV diagnosis I was always looking for any slight sign that he was getting sicker and deteriorating. The uncertainty of what might happen always played on our minds.

15. A decision was made to tell only a close number of people of H status. However, unfortunately word spread and his employer found out, which caused a great deal of upset for H He wanted to try to lead as normal a life as possible without any prejudice.

16. Living in silence due to the media pressure, fear of discovery, stigma and prospect of ostracisation, due to the diagnosis, was a further burden to carry. The campaigns which were undertaken by the Department of Health created hysteria, to the extent that sufferers were ostracised in the community if their diagnosis was made public.

17. H was admitted to GRO-B Hospital early one morning in GRO-B GRO-B after feeling very ill. Three days later H died, during what was deemed as a minor

procedure (bronchoscopy), to establish the cause of his illness. H had called me the night before the procedure to say 'whatever happens we will always be together'. I believe that H knew that his admission into hospital was more serious than he initially made out.

18. I kept a personal diary at this time and made reference to H diagnosis. I also referred to conversations I had with medical staff following his death.

19. The timeframe and the circumstances surrounding H death warrant investigation as to whether any further medical mistake occurred.

20. I remember being told about H death and I was informed that the doctor performing the bronchoscopy was extremely upset that he had died during the procedure. This was a very rare event for something like this. His death was such a shock to everyone who knew him as it was so sudden. I also noted in my diary that GRO-B who had known him for years came in to talk to me – she was devastated'.

21. His death certificate confirms that there was a post mortem without inquest.

22. As far as I am aware there was no record of H suffering from Hepatitis, unless stated in any records unknown to me.

Career

23. During the years between GRO-B H studied at GRO-B College of Higher Education and received a Diploma in Art and Design (which included Advertising).

24. H went on to work in the advertising industry and secured a role as a copy writer. He worked at various advertising agencies, including GRO-B the agency he was working for when he died. Prior to working at GRO-B he was headhunted by other top advertising agencies. He went on to write and win/share awards for many campaigns and TV adverts, including political campaigns and British Airways.

25. H was well known on the London comedy circuit where he appeared in improvisation and stand up comedy shows. He was extremely funny, sharp and quick witted and he also appeared at the Edinburgh fringe festival.

26. H was an accomplished artist and talented writer. He wrote poetry and short stories, although he never considered these good enough to be published. He also had an ambition to write a screenplay, but sadly he never got the chance.

27. Anyone who met H would describe his personality as thoughtful and contemplative, very generous, a larger than life character who was extremely clever and talented. He was very sociable and popular and had many close friends. He was very courageous and remained determined right to the end.

Section 3: Consent

28. I believe that H was treated without being given any information whatsoever regarding the risks of being exposed to the HIV virus/infection from Factor VIII products. H had every faith that the Factor VIII he was injecting on such a regular basis was supposedly saving his life and preventing him from bleeding to death.

Section 4: Impact

29. When our relationship began, I was realistic in what to expect in terms of his symptoms in relation to his Haemophilia diagnosis. We were very young and enjoying our life and so did not dwell on it so much.

30. H knew how much I wanted to start a family, so on occasions when this was discussed he would suggest I find someone with whom I could have children. This was not an option. Our love and commitment to one another cost me the opportunity of having children. The loss of H and the loss of ever having children has impacted greatly on my emotional wellbeing. Although these events occurred many years ago, I still feel I have not really come to terms with everything that happened. I still feel an enormous and overwhelming sadness of what might have been, the life we could have lived and the children we could have had, without the HIV diagnosis.

31. I lost H when he was only GRO-B and it still saddens me that many of the people who attended the wedding reception, attended his funeral only six months later. The fact that he passed away following a bronchoscopy, which is deemed a minor procedure made his death very difficult to accept.

32. After his sudden death, I was left in complete and utter shock. I remember being totally numb, and even the smallest errands became a blur. I attended a friend's wedding some time after H passed away and I felt like I was not even there, that I was watching it from afar.

33. Prior to H death, I had been employed as an Advice Worker in the Education Department at GRO-B Council. However, following the bereavement and trying to come to terms with his untimely death, I was unable to work for many months. I was signed off sick by my GP for periods of 3 months at a time and during this period I attended bereavement counselling. However during those sessions I recall repeating the same things over and over again. This usually concerned our final hours together and arriving at the hospital the following day to be informed he had died. I did not feel I could move forwards and spent many hours alone in our flat in tears. I missed him so much and felt very lonely, despite the fact that I had support from my family and close friends. To make matters worse my friends were all getting on with their lives, getting married and having children. I felt life was very unfair and that I was at a standstill.

34. Two years after H died, out of necessity, I had to begin to contemplate my future, sadly one without him. I had a mortgage and other regular bills to pay all of which were very costly. Luckily my family were able to help me financially during this period.

35. After very careful consideration I decided to change career path and train to be a nursery nurse. I enrolled on a 2 year course at a local college as a mature student. Most of the other students were 16-18 year olds but there were a few who were older, so I was able to make friends and fit in. Training and subsequently working with children was a way of compensating for not having any children of my own.

36. When I completed the course, I found employment straight away and I started working with pre-school children with profound and multiple learning difficulties. This is not the

most lucrative of professions but working with these children was very rewarding and surpasses any monetary gain. I stayed in this role for over twenty years and really enjoyed the work.

37. I remained single for over six years following H death. I did not feel as though I wanted to meet anyone. I felt that people I may meet would become frustrated with my persistent talk and reminiscing about H I continued to keep a diary for 3 years after he died and often mentioned him. I had expected to spend many happy years with him but I was robbed of this.

38. I met my current partner in October 1998. We moved in together in August 2000 and were married in July 2004. We have now been together over 22 years. Unfortunately it became apparent that it was too late to have children. It was later discovered that I had fibroids and the hospital suggested that I have a hysterectomy, which I refused. Instead I opted for a less invasive procedure as even though I was now past child bearing age I was still unable to cope emotionally with such a drastic operation.

39. I had desperately wanted to have children of my own but unfortunately this did not happen and is still a huge regret and continues to cause me much sadness. Freezing my eggs was something that I wasn't aware was an option at the time.

Section 5: Treatment/Care/Support

40. As far as I can recall we were not offered any counselling following H HIV diagnosis. There was no support from his GP practice, or any other form of counselling. However, the doctor who looked after H at GRO-B hospital Dr GRO-B would have supported him, as my recollection is that H thought very highly of her and she had known him for many years. The bereavement counselling I had when H had died was organised through my own GP practise.

41. Even when H diagnosis of his HIV status was delivered over the phone, no follow up support was offered as far as I am aware.

42. It was almost impossible to seek support from both family and friends due to the stigma attached to HIV, therefore very few people were made aware of H condition.

But inevitably people began to find out including his employer which really upset H

Section 6: Financial Assistance

43. We received a one-off payment of £20,000 from the Macfarlane Trust which was paid while H was still alive.

44. In order to receive this payment, we were made to sign a waiver that no further action would be taken.

45. H received a mobility allowance, which he used to travel to and from work by taxi, when he was in too much pain to travel by public transport.

46. Due to the lack of funds and also to the waiver that we signed, we did not pursue litigation.

Section 7: Other Issues

47. I have a number of concerns regarding H case that I believe need to be addressed during the Inquiry. I am unsure as to why there was a delay in providing a diagnosis as H was not tested/diagnosed until 1986. In addition, there was no consultation with H or myself regarding the inherent risks of the treatment that he would be receiving. As a result of no consultations or testing being provided by the medical professionals, I had to take it upon myself to take the necessary steps to ensure my safety.

48. I also think about what medical checks should have been carried out in relation to Hepatitis, as there was clearly a significant risk of the condition for H

49. In addition, the cause of death which was recorded on his death certificate as Acute Pneumonia is not entirely accurate. I kept a diary in GRO-B and one entry, a week after he died, said 'We went to the coroners office to fetch the registration to register his

death. In the morning the office rang to say he died of acute pneumonia, absolutely nothing to do with the test they'd carried out'.

50. However, this was in conflict with what I was verbally told by two different doctors at GRO-B hospital. The diary states on the day he died 'I was really crying by this time as they tried to explain what happened. He'd started to have some sort of seizure and the team had tried to revive him for over twenty minutes but his heart wouldn't start. They'd taken what they wanted from his lungs and later told me he had developed PCP (Pneumocystis Pneumonia) an Aids related condition of the lungs'.

51. Another entry a week later refers to a conversation I had had with a registrar at GRO-B GRO-B He had spoken with the people who had carried out the post mortem. I wrote 'I found out quite a bit including the PCP that H had had in his lungs was definitely the start of the AIDS virus and that it would have had to be controlled by antibiotics for the rest of his life'. I went on to record 'The doctor also said that there was no evidence of any bleeding at all in his stomach and the excruciating pain he experienced was the PCP making its way down from the lungs. That would account why the factor VIII he had taken, hadn't taken away the pain and why the hospital hadn't given him any factor VIII on his admittance'.

52. This has invariably led me question why no reference was made to this on the death certificate. I probably should have picked up on this at the time, but was unfortunately not is any fit state to do so.

53. I therefore question whether if under recording of deaths from HIV and related illnesses was the norm at this time, especially in light of H having to sign a waiver that he would not seek litigation.

54. As a severe Haemophiliac H relied on Factor VIII to stop him bleeding to death. The very medication that should have saved him ended up killing him in the prime of his life. His hopes, dreams and ambitions were brought to a sudden halt on receiving the devastating news of his infection with the HIV virus. My hope for The Inquiry is that the truth of what really happened and who is responsible for the death of H is found out in order to provide closure for me and justice for H Even though visiting these events, after so many years has caused me huge upset, I feel I have a

duty to pursue this on behalf of H who is not here to represent himself. It is imperative that the level of negligence experienced by H the pain he suffered and the pain endured by his loved ones never happens again to anyone else.

Statement of Truth

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

Signed GRO-B

GRO-B

Dated 15th April 2021