

# ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN3771001

Exhibits: Nil

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 1 October 2019.

I, GRO-B will say as follows:

### Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1985 and my address is known to the Inquiry. I live in Glasgow. I am currently unemployed. I intend to speak about my infection with HIV which I contracted in utero from my mother after she was given contaminated blood during the birth of my older brother. In particular, I intend to discuss the nature of my illness, how the illness has affected me, the treatment received and the impact it had on my life and that of my family.

**Section 2. How Infected**

2. My mother  was born in Glasgow. At a young age she moved to London. She then met my father  They married in 1980. She was 20 years old. The following year, she gave birth to my brother  at what was then  in  During labour she haemorrhaged and was given a blood transfusion to save her life.
3. As far as I am aware my mother's health was fine. Two years later in  1982, she became pregnant with my older sister  and returned to Glasgow. She had a natural birth with  and there were no problems.
4. In 1985, I was born in  in  At the time my dad was a senior social worker at  a children's home   my youngest sister was born   in  1986.
5. My older sister became unwell. She had been hospitalised on a number of occasions with pneumonia and thrush. These are typical symptoms of immunosuppression and are indicative of possible HIV infection. She underwent numerous tests at  When her health deteriorated, she was transferred to what was then  in Glasgow as this had an infectious diseases unit. My parents were asked to do a HIV test. They tested  first, the results of which came back positive. The whole family

## ANONYMOUS

were subsequently tested. It was revealed that each of us were HIV positive except GRO-B. My parents discussed their medical history with the doctors. They were questioned on their sexual history and if they had ever taken drugs. They found this devastating as they had neither of them been like that or taken drugs.

6. As far as I am aware, my parents were not given any information or advice before receiving the transfusion regarding the risks of being exposed to HIV or any other infection.
7. In 1987, following the diagnosis, we returned to GRO-B. I had just turned two years old.
8. S1 started school and had to go to school in a pram because walking was difficult and her legs got tired very quickly. Her health continued to deteriorate. In 1988, she was hospitalised with pneumonia. My parents brought her home at Christmas that year because they wanted one last Christmas with us all together. On GRO-B GRO-B 1989, S1 died from pneumonia as a result of AIDS. S1 was just 5 years old when she died.
9. During this time my younger sister S2 was also very unwell. S2 died of an AIDS-related illness just GRO-B after S1's death on GRO-B 1989. She was just 3 years old when she died.
10. My dad was taken into GRO-B in GRO-B 1993 with pneumonia and severe weight loss. He was diagnosed with HIV dementia in October 1993. The HIV infection was acquired as a result

of my mother's infection. He died in GRO-B 1993, aged 43. He was on AZT at this time.

11. My mother died on GRO-B 2013, aged 43 years, from HIV-related causes. I was then 28 years of age.

12. I do not believe I was given adequate information to manage my infection. The origin of the infection wasn't revealed to us. As a family, we had to work this out. I feel I should have been told what the cause was as this would have helped me defend myself better at school from all the insults and bullying. I was only told that I had something in my blood that could make me unwell and I had to be careful around other people if I had a cut because I could pass it on or pick up infections from other people.

13. As the risks of contracting HIV were not communicated to my parents prior to receiving a transfusion, they were not aware of their own HIV status nor the risks of transmitting the virus in utero to their unborn children.

### **Section 3. Consent**

14. Whilst I do not believe that my mother was treated without her knowledge or consent, as indicated earlier, I believe that she was not given adequate information as to the risk of contracting HIV. She was therefore unable to make an informed decision as to whether she should have a transfusion.



15. As previously indicated, I also believe that I was not given adequate information regarding the origins of the virus or the most appropriate treatment following my diagnosis. I was 9 years old when I commenced anti-viral medication.

#### **Section 4. Impact**

16. HIV has had a devastating impact on the lives of my family and I. Excluding my brother GRO-B I am the only one left in the family. They have all died of AIDS-related illnesses. I have had to grieve the loss of my mum, dad and two sisters and witness their grief too.

17. Shortly after S1 died and whilst S2 was very unwell, my mum stopped eating. She almost didn't make it to S1's funeral.

18. Life was difficult after S2's death. My parents were grieving whilst trying to bring up two other children GRO-B and I felt the loss of our sisters. I particularly felt the loss because I shared a room with both of them. I was close to my younger sister. I was very protective of her. I was only three at this point. My mother wasn't working. My dad threw himself into his work. He wasn't at home very much during this time. My mother was struggling but she had two other children to take care of. My parents relied on our maternal grandparents quite a lot. My

## ANONYMOUS

grandad would drive to GRO-B on a regular basis to help out. My mum had two brothers and a sister who were also very supportive.

19. My mother and I were often unwell. My grandmother was also unwell and my mother would have to care of all of us. At times, we had quite a fraught relationship as a result. This was made worse by the financial issues my mother suffered particularly after my father died.

20. My family and I have been subjected to a significant degree of stigma following our diagnoses. When my sister S2 was first diagnosed with HIV, she was immediately put into isolation. Doctors and nurses wore masks and hazardous material suits. When the doctor from GRO-B informed our local doctor from GRO-B about the diagnosis, the local doctor went into the room where my sister was being kept and put her on his knee. He said, 'she's just a little girl, she's scared. Yet there's all these doctors walking around with masks on treating her like she's a leper.' I can imagine that this must have been heart-breaking for my parents to witness.

21. Growing up, the media persistently intruded upon the lives of my family and me. Shortly after we received our diagnosis, the Scottish news got hold of it. I am not sure how they obtained this information. The headline television news read: GRO-B family hit by AIDS.' From thereon, the papers and press camped outside the front door. We were subjected to a constant barrage of news intrusion. The press came to both S1 and S2's funeral. They took photos of the hearse and people coming in

and out of the church. At one point, they tried to enter our home. News of my father's death was also leaked to the press. My grandad had to drive to GRO-B in the middle of the night and cover us in blankets to take us back to Glasgow. The press intrusion lasted until the New Year. I was then aged 8 and GRO-B 12. We stayed at our grandparents during this time for our protection.

22. As GRO-B and I grew up, we often felt there were conversations taking place behind closed doors and that there were secrets being kept from us. On one occasion, we looked up the newspaper articles and the headlines without my parent's knowledge. The two of us just cried when we saw them.

23. The media's portrayal of my family contaminated the opinions of those living in GRO-B who made assumptions about how we had contracted the virus. At the time GRO-B had a population of just a few thousand. It was a very close-knit community composed of families who had been living there for generations. We were not only considered a new family but a new family with AIDS. We didn't go out as a family because of the stigma. My mum wrapped us in a bubble to protect us. If we went to the park it was only in Glasgow with my grandparents, well away from those who might know us back in GRO-B. When GRO-B had been due to start school, parents protested in order to prevent her going to school with their children. Fortunately, the headmistress at the school and some of the members of the PTA stood up for my sister and said that every child deserves an education.

24. My infection with HIV has significantly impacted upon my health. I suffer from oesophageal strictures, which I have to go into hospital to have widened. I also have multiple episodes of oral thrush. At one point this required me to have a nasal gastric tube for nutrition and medication to be administered. However, this coincided with me starting college and as I didn't want to start college with a tube in my nose, a peg tube was inserted into my stomach instead. I have had this for almost 10 years. My medication was being fed through it as well. I have suffered from recurrent candida and bouts of pneumonia. I have had MAC lung disease which is a type of TB and pre-cancerous vaginal cells. I have also had persistent problems sustaining a healthy weight. I suffer from peripheral neuropathy which is a lack of sensation caused by the HIV medication. This has led to multiple burns on my stomach and my thighs. I've also got dentures. I have had multiple seizures which I believe to be HIV-related. On one occasion, I banged my head. The pupil in my left eye enlarged and never returned to normal. I developed a cataract and now have no sight in my left eye.

25. For the first 10 years following my diagnosis, the only treatment I received in relation to my HIV was immunoglobulins to boost my immune system. I wasn't given anti-viral medication because I was told there wasn't much available at the time. I believe this ought to have been made available to me earlier.



26. I have had multiple bouts of antiviral therapy which carried many side-effects. Taking a number of different drugs from aged 10 creates huge psychological issues. In 2005, whilst on holiday in Lourdes with my mum and my grandmother, I suffered a psychotic episode. I was having visions and thought people were trying to poison me. I tried to attack my mum and my gran. I had to be sedated on the plane home. Upon my return to Glasgow, I was admitted into hospital. It was thought that I may have had a swelling on the brain. It could also have been a symptom of the candida or the antiviral medication. I was discharged a couple of weeks before GRO-B's wedding. I was a bridesmaid but had to have people sitting near me in case I experienced another episode.

27. My HIV status has caused problems in obtaining medical treatment.

When my mum first tried to register us with a dentist, the local dentists wouldn't take us because of our status. I eventually spoke to the consultant in GRO-B who referred us to the dental hospital in GRO-B about 20 miles away.

28. I have suffered psychologically, not only from my own HIV status but additionally the impact it has had on my relationships with my family.

GRO-B and I have had a fractured relationship. I blamed GRO-B for my illness and for my sisters' deaths. If my mother hadn't haemorrhaged during the birth of GRO-B none of us would have contracted HIV. GRO-B felt a lot of guilt as well. In hindsight I know it wasn't his fault.

## ANONYMOUS

29. After my mother's death in 2013, I went into a downward spiral. I didn't care if I lived or died. I had been living with my mum but no longer felt able to look after the house by myself. I moved out to stay with a friend who was also HIV positive. I was unhappy there and spent most of my time shut off in my room. I suffered quite serious depression during this period.

30. My HIV status has significantly impacted upon my education. Throughout school, I had a number of hospital admissions which disrupted my education and made it difficult to keep up with the work when I returned to school.

31. I was also subjected to a significant amount of stigma and bullying at school as a result of my HIV status and the illnesses I have suffered as a result. I began secondary school on crutches. This was because about a year prior, I suffered from osteomyelitis, which is an infection of the bone. I was in a chair the whole time I had the cast and for nine months after the cast was removed. I also had an infection in my bloodstream. This gave people a reason to pick on me.

32. The majority of the time I was treated like anybody else. However, there were incidents that stick in my mind. For instance when I used the toilets girls would wait for others to leave the toilet in order to use

## ANONYMOUS

their cubicles instead of mine. When I told them that my toilet was free, the girls would say, 'but I might catch something'. Other children wouldn't sit next to me. I wasn't invited to parties or sleepovers. I don't believe the school made any effort to educate students on HIV or how it might be transmitted. In the playground I would be tormented by the other children. People would make remarks that I had AIDS or they would quote the headlines such as 'AIDS family' or 'you've got dirty blood'. I would just ignore it. I have always just tried to get on with my life. The worst thing is for someone to keep trying to bring you down, in relation to an illness, over which you have no control. The bullying continued until I was 16, whereupon I left school.

33. The recurrent problems with my health have prevented me from having a career. I am currently unemployed. I cannot hold down a job anymore. Growing up, most of the jobs I had were in local bars or restaurants. Jobs I got through family friends. I would have loved to have worked with children. However, even the short time I spent on a childcare course taught me that parents wouldn't be happy to have someone with my status caring for their children.

34. I have been receiving benefits since I was 10 years old. Recently, the government took the mobility component of the PIP benefit away from me. If you can walk more than 100 yards, they take it from you. This has had a substantial effect on my finances. I do not know how many appeals or case hearings I have been to. How many times do I have to prove that there are things I cannot do? One day I might be able to go

shopping and the next day I won't be able to get out of bed. In order to afford the fares travelling to and from hospital for appointments, requires me to cut back my expenses in other areas.

35. My HIV status has impacted upon my romantic relationships. I have had relationships but not anything serious. This was mainly because of my fear of transmitting the infection to a partner.

36. I was told that I could live a normal life with HIV. For me, with all the side-effects and the mental and emotional effects of living with HIV, I will never see my life as being normal.

37. Throughout my whole life, it has always felt as if so much was expected of me. I have felt enormous pressure from doctors and family to succeed as I have had chances that my sisters didn't have. People would say GRO-B you're going to get through this', 'You're the survivor'. I have been fighting for 34 years. There's going to reach a point when I've got no fight left in me, when I say enough is enough. People will have to accept that.

#### **Section 6. Treatment/Care/Support**

38. I was at GRO-B Hospital until my 19<sup>th</sup> birthday. I wasn't offered any counselling or psychological support. There are not many areas of my life that are private but there are certain areas that are personal to me that I don't want to share with others. In retrospect, I believe that therapy would have been valuable to me. I had no one with



## ANONYMOUS

which I could share these personal aspects of my life. When I was transferred into an adult hospital, I felt as if I'd been thrown into the pool with no armbands. Prior to this, I was treated as a child; decisions regarding my treatment were made by my mother and doctors on my behalf. Then suddenly, I was on my own.

39. In more recent years I attended a hospice. I appreciated the fact that they didn't fixate on my illnesses, but how I was coping emotionally and mentally. I found this helpful.

### **Section 7. Financial Assistance**

40. Neither my family nor I have received any financial assistance from any Trusts or Funds to support us through our illnesses.

### **Section 8. Other Issues**

41. I just want justice for my family. I want someone to take responsibility for what has happened. I believe that the government and medical staff were aware that blood and blood products were contaminated but they didn't inform those who had received contaminated blood. This meant that people like my mother, unaware that she was infected, continued to have more children, whom she unwittingly infected. I believe the government and medical profession have covered up their decisions. None of this should ever have happened.

# ANONYMOUS

## Statement of Truth

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

Signed

GRO-B

Dated 12.12.19