

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN7475001

Exhibits: Nil

Dated: 5 December 2022

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 5 November 2018.

GRO-B will say as follows: -

Section 1: Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** and my address is **GRO-B** In this statement I intend to speak about my son's infection with HIV following a blood transfusion. In particular, the nature of his illness, how the illness affected my son and I, the treatment received and the impact it had on my family and our lives together.

Section 2: How Affected

2. My son [GRO-B; S] was infected with HIV when he was born on the [GRO-B] 1985. I gave birth to [S] by emergency c-section at [GRO-B] in [GRO-B]. The placenta was coming away from the womb and the baby was not getting enough blood or oxygen. [S] weighed 9lbs at birth and was put straight in an incubator and onto a ventilating machine. At this time, [S] was given a blood transfusion. [S] was also prescribed phenobarbitone powder to add to his milk to prevent seizures. The doctor advised that at this stage we just had to take it day by day.

3. 6 months later the family doctor visited my home and advised me that [S] had contracted HIV. When the GP came to my house to advise me of the infection he said "I didn't feel comfortable coming down to tell you this bad news." The GP did not stay for long, and I was devastated. [S] had not been tested at this stage; this conclusion must have been drawn because the blood was infected. There was no notice of the doctor's visit and I felt like this bad news had just come out of the blue. The doctor came into my house, advised me that my son had HIV and then left. I do not believe that the doctor went into depth about the infection, although I was in shock at the time.

4. I did not know very much about HIV at the time of [S] diagnosis. I do recall seeing headlines about HIV when Rock Hudson passed away and when the BBC Tombstone Adverts were aired. I felt as if we had just been left to get on with it.

5. After [S] diagnosis, we then had an appointment with a specialist doctor who provided us with some further information. [S] was then started on immunoglobulin every 3 months, which later became less frequent at every 6 months. I recall that [S] was on a clear drip during his time at [GRO-B] [GRO-B].

6. At the time of the transfusion, we were not provided any information about the risks of having a blood transfusion. After the emergency c-section, I was still

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under anaesthetic and [s] was whisked away and put in an incubator. I was given a photograph of [s] when I woke up. I am not sure whether I was told at this stage that [s] had been given a blood transfusion. I am sure that they would have told me that he was on a ventilator at this time, but it is very difficult to recall exact details. We were advised of the HIV six months later.

7. I believe that this would not have happened if due consideration had been given to the warnings at the time. I am aware that information about HIV is now more at hand than it was in the 1980s. The information potentially could not have been communicated to me earlier, however risks of a blood transfusion should have been communicated to me prior to my son being given a transfusion.
8. I was advised of the risks of cross-infection. I was advised that I did not need to tell anyone at [s] school or at the hospital because they should be treating every person in a way that would avoid cross-infection. I did need to tell a local hospital of [s] infection on one occasion because it was not the usual hospital that we attended, and the nurse treating [s] was not wearing any gloves. I was aware of the risks of cross infection and advised her of the infection in order to reduce any risk to the nurse. I hated having to do this as we had purposely visited [GRO-B] in [GRO-B] because it was less local.
9. Both of my sons were visited by Dr Tarnamordi as [s] was becoming a teenager. I remember [s] asking if he would never be able to have a girlfriend. [s] was advised that if he was ever in a relationship, he would have to inform them of the infection.

Section 3: Other Infections

10. I do not believe that my son received any infections other than HIV as a result of being given infected blood.

Section 4: Consent

11. I do not believe that [s] has been treated or tested without my or his knowledge, without my or his consent or without being given adequate or full information.

12. I do not believe that [s] has been treated or tested for the purposes of research.

Section 5: Impact

13. [s] HIV has had a significant impact on his life and on mine since his diagnosis.

14. I have constantly had to take [s] up and down to hospitals over the years. Sometimes I was alone, and I recall becoming overwhelmed and breaking down on the way home on numerous occasions. It was always me who took [s] to the Hospital. I do not drive so I had to take him on the bus. My ex-husband did not come with us, because of work, but sometimes my mother accompanied us. The hospital visits were constant reminders of [s] infection.

15. There has been a lot of bitterness, hate, anger and tears. I would get very emotional any time it was brought up. Sometimes, I would wish that the hospital visits were less frequent. I felt that these were a constant reminder of the situation. I would go straight to the doctor if there were any issues with [s] I had to juggle this with work and with another child. [s] has not been to the hospital recently because of the Covid-19 Pandemic. [s] is anxious about being on a bus and refuses to attend. Prior to Covid we would attend regularly, however this is no longer the case.

16. When [s] was at Primary School, he had to get injections from the hospital any time there was an outbreak of the Chickenpox. [s] was on numerous tablets each day and at one point I recall he was on 12 tablets each day [s] now takes 2 tablets each day to manage his infection. There has been some issues with the tablets prescribed in the past and we have had to look for other

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solutions. Sometimes [s] refused to take his tablets because they tasted horrible, like metal. We were reminded often how expensive this treatment was.

17. My father and my best friend both live in Australia. When we visited the first time, I advised my best friend of the infection because she had 3 young boys. I was concerned that if the boys were playing, this could increase the risk of cross infection. This did not change my best friend's attitude to me or to [s], and we remain friends. When my best friend visited from Australia recently [s] would not hug her, he waved at her from his balcony.

18. As a young boy, [s] did not like going to sleepovers as he was on a lot of medication, and he did not want this to be noticed by his peers. [s] often said that he did not want to go to his friends' houses.

19. The medication that [s] was on was very new and at the time there was no guarantee of success. No one knew what the outcome would be. A couple of years ago [s] was referred to a specialist as there was something in his blood that required further investigation. The doctors were worried about [s] bone marrow. It was at this time that I found out that [s] had chronic kidney disease. From there, the specialist found that [s] had chronic kidney disease. [s] does not drink or smoke due to his medication. This was discovered very soon before the coronavirus pandemic lockdowns. [s] locked himself away during the lockdowns and would not see his family.

20. At one point, I felt like everything got on top of me. I overdosed on paracetamol and vodka. I crashed out and woke up in the early evening. My ex-husband and Mother-in-Law were there, and I asked why they did not get a GP. I do not remember anything from that morning.

21. I became overwhelmed and felt like I was unable to cope. I had attempted suicide and my Marriage was on the rocks, eventually leading to divorce. I spoke about the infection but my husband at the time would not. I found out that I was pregnant again and we were very worried. My husband and I fell out on the day of my younger son's birth. This birth also required a c-section and my

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husband stated that history was repeating itself. Over time, we drifted apart. We were able to tell both sets of our parents about our divorce at the same time.

22. I know that [s] is also bitter and angry, and that he sometimes takes this out on me. It is always the nearest and dearest that suffer the most in these situations. This makes me upset, but I know that [s] loves me as much as I love him.

23. I asked [s] if he would consider counselling to help manage the mental impacts of his infection, but [s] did not want to bring up the past. I suffer from depression, and I have been prescribed fluoxetine in the past. I was put in touch with counselling, but I couldn't bear it. I felt like counselling was just a reminder of what we had been through.

24. Once I visited [s] flat and I wondered why he appeared so withdrawn. [s] said "Mum, what's the sense in going on?" and I told [s] not to think like that. I have a key to [s] flat and I am concerned about visiting and finding him lying there.

25. [s] does not drink or go out; he does not mix with friends and has no interaction in real life. [s] has some friends that he speaks to on gaming platforms, but he does not see friends in real life. [s] did not have the years as a teenager that he should have had, I sometimes feel like he is just existing.

26. [s] has never had a relationship as a result of his infection. I feel that he has missed out on this aspect of life – I would have loved to see him married with children. [s] never talks about this.

27. [s] is now in his 30s and still has hospital visits and blood checks. I have not pushed visits to [GRO-B], and [s] has been able to do more things by himself recently.

28. In his 20's [s] was complaining of tiredness & breathlessness for a fortnight and his father took him to a local hospital. They scanned [s] and saw a

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shadow but concluded that it was not pneumonia. After there was no change, [s] went to [GRO-B] where he was kept in for pneumonia and lack of oxygen in the blood.

29. Just before Covid, [s] had extreme headaches and nausea. Around eight o'clock one evening we were discussing that [s] had had severe headaches for around a week or so. We called the paramedics. Originally, [s] went to [GRO-B] who then advised that he was taken to [GRO-B]. The Doctor organised a head scan for [s]. Around this time I became overwhelmed and I had to seek assistance from [s] dad. After this, [s] asked me to cancel all of his appointments, so I did.

30. The physical impacts of [s] infection were more noticeable at High School. We did not speak about the infection much. The hospital visits were regular and this would have been disruptive, particularly in his teenage years.

31. There were no difficulties or obstacles in accessing medication, nor am I of the opinion that there were medications available that were not made available to us.

32. Both of my sons used to go to the dentist together. They were seen at the very end of the day. I now do not know when the last time [s] went to the dentist was. I believe that he has not gone for years. Both of my sons and I used to visit the dentist very regularly.

33. I recall on one occasion being in the hospital with [s] and the doctor asking if he had contracted HIV from my breast milk. I was offended that the doctor had asked this, and I told the doctor to look through [s] notes to see that the source of infection was from contaminated blood given to [s] at this hospital.

34. [s] infection has had an impact on my private, family and social life. I had to get my hours changed at work. I do not drive, so a lot of time is spent on the buses to and from the hospital. I did go out sometimes, but [s] infection

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was a significant contributor to the end of my first marriage. My husband used to bottle up emotions.

35. On one occasion, right before the coronavirus pandemic, my ex-husband had taken my son out to a pub. The man at the bar said that he would not serve my ex-husband because his son had HIV. I am not sure how this would have been known as we had kept the infection a secret. My ex-husband left the bar with my son. If it had been me, I probably would have been straight to management. My other son told me about this encounter, and my ex-husband has still not mentioned this to me.
36. We have kept [s] infection to ourselves even though the infection was no fault of our own. I wish we would have been able to be more open, but the man in the bar proves that the risk of being affected by the social stigma of having HIV still remains.
37. [s] has always been close with his brother [GRO-B]. They lived together and [GRO-B] felt guilty about getting married and moving out. [GRO-B] was worried about his brother. Especially over the last two years, it has been very difficult for [GRO-B] being unable to see [s].
38. My mum has only seen [s] once over the pandemic. They had a chance meeting in the street and it was quite emotional for both of them. [s] was frightened and anxious about seeing people because of Covid.
39. [s] went to college but is unable to work because of his infection. For a time, [s] was volunteering but unfortunately [s] lost a lot of weight because of his illness. His spine and bones were protruding. For his volunteer work, [s] had to carry a weedkiller on his back. The new site manager and some other lads volunteering picked on [s] and he stopped volunteering.
40. [s] does not speak much about his infection unless it comes out in anger. We have never discussed this as a family, and I have asked him to go to counselling, especially when he said he could not go on.

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41. [s] owns the flat that he lives in. All of the money from SIBSS accumulated as he does not socialise and he was then able to buy his flat outright.

Section 6: Treatment/Care/Support

42. I encouraged [s] to attend counselling, but he did not wish to do so. [s] did attend some small group sessions with others in similar situations, but he felt that this made him more depressed. [s] only attended this once. I believe that the group was in Fife or Perth. [s] has been invited to other sessions but he refuses. [s] was offered some counselling by the NHS but he declined.

Section 7: Financial Assistance

43. [s] has received financial assistance because of his infection. Originally, [s] received assistance from the MacFarlane Trust, but now he receives support from SIBSS. [s] receives monthly payments from SIBSS and has also received the interim payment.

44. I am not aware of any difficulties in applying for financial assistance.

Section 8: Other Issues

45. I wish to remain anonymous throughout this Inquiry

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Statement of Truth

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

Signer

GRO-B

Dec 9, 2022

Dated