

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN0827001

Exhibits: 0

Dated: October 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

Section 1. Introduction

1. My name is **GRO-B** and my date of birth is the **GRO-B** 1985. I live at **GRO-B** **GRO-B** with my husband **GRO-B** I work as a **GRO-B**
2. I make this statement in relation to **GRO-B: SF** my step-father who was born on the **GRO-B** 1958 and died on the **GRO-B** 1998 as a result of being treated with contaminated blood.
3. **SF** married my mum, **GRO-B** (my mum) **GRO-B** when I was 6 years old. My mum has made a statement to the Inquiry **GRO-B**
4. This witness statement has been prepared without the benefit of access to **SF** s full medical records.

Section 2. How Affected

5. I wish to refer to my mother's statement in relation to this information.

Section 3. Other Infections

6. I wish to refer to my mother's statement in relation to this information.

Section 4. Consent

7. I wish to refer to my mother's statement in relation to this information.

Section 5. Impact

8. As a child I knew **SF** had Haemophilia and when I was getting to know him, he was quite well. It was not until I was about 11 years old that I was told of his HIV condition.
9. **SF** developed ascites and he was concerned about how he looked so he did not like to go out, he was embarrassed by it. He also developed lymphoma and received treatment for it at the **GRO-B** Hospital during the summer of 1998. He also had cirrhosis. His illness was gradual, although due to my age he would have tried to shield me from the reality of his conditions.
10. **SF** went into hospital on the **GRO-B** to try to make him more comfortable for **GRO-B** by draining the ascites. However during the time he was there, between the **GRO-B** 15 litres of fluid were drained and he went into organ failure. He had withdrawn his consent for the treatment but they had continued anyway.

11. I went to the hospital with my mum on the **GRO-B** and whilst we were there his condition was deteriorating. At one point he got out of bed and tried to rip off the cannula from his hand. This really upset me and has had a lasting impact on me. When I had surgery in 2021, just being told I had to have a cannula made me cry.
12. During the evening of **GRO-B** the doctor told us **SF**'s main problem was stress and that we should go home even though it was late at night. At the time it felt like he was saying we were the cause of **SF** being ill. This has always stayed with me.
13. As it was late and mum didn't want to go far from the hospital we checked into a nearby hotel and ordered room service. Before we had even eaten the hospital called and told us **SF** was unlikely to live through the night.
14. We rushed to the hospital and as I could run faster than mum I ran on ahead. When I got there **SF** was naked and being held down by multiple nurses while they were doing something to him and he was struggling. I was very distressed by this and was told to go out and wait in the nurses' room. It was around 1.30am and I was expected to go and sit on my own in a room in a dark corridor while **SF** was dying. I refused.
15. During the last hours of **SF**'s life no one seemed to be trying to save him. The nurses did not seem bothered and one of them was reading a 'Hello' magazine. One nurse was sat in the corner of the room with us. **SF** did not seem to be breathing and I started calling him as I was scared he was dying. The nurse told me to stop and said he needed to sleep. Then she jumped up and checked **SF**'s pulse and realised he had died. It was awful, I felt numb and didn't know what to do. We waited at the hospital for my father to collect us and drive us home as mum was not in a safe state to drive. I can remember the sun was rising as we left the hospital.

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16. [SF]'s death, at that point, was unexpected. It was a real shock. He had cleared the lymphoma and I was expecting him to get better.

17. He died on [GRO-B] we had all bought presents for each other [GRO-B]
[GRO-B] It was so hard going home and seeing them there. If he had been told of any risk of having the procedure, I am certain he would not have had the treatment before [GRO-B] Every year I find [GRO-B] difficult with certain songs upsetting me every time as it brings everything back. The repetition of traditions makes his death being at [GRO-B] so much harder as there are so many reminders year after year.

18. After [SF] died we found that a 'Do Not Resuscitate' notice had been placed in his notes but we had not been consulted about this.

19. Due to my age I had been shielded from the effects of [SF]'s illnesses but during what turned out to be his final year he could not hide it anymore. He was throwing up his food for weeks on end when he had the tumour and it smelt, he also had puss coming out of his nose. It was terrible to witness.

20. At school I had to keep [SF]'s illness a secret from everyone, even my closest friends. Only close family and very long term select friends knew; there was a lot of stigma attached to HIV. Because no one knew what had actually happened, it meant that we had no support and as a 13 year old, I had to deal with this in secret and on my own.

21. It was hammered home to me not to speak about [SF]'s HIV to the extent that it was almost a relief when [SF] developed cancer as it was something we could tell people. We no longer had to make up excuses for hospital appointments. It was something we could talk about openly and people knew.

22. My best friend said recently that she did not remember any of this happening, this really highlighted just how much I had kept secret. She didn't remember because she never knew. The secrecy was very stressful. I also had to be careful not to bring germs home as **SF** was immunocompromised. This felt like a huge responsibility.

23. I tried not to let it impact me but it was very difficult. I would often stay at my friends' house during the summer of 1998 as **SF** was in hospital in London, **GRO-B** **GRO-B** and mum was staying up there with him. **SF** was on an AIDS ward and my mum did not want me to witness it. She spent time with him at hospital thinking he was about to die.

24. During the Summer of 1998, **SF** was not working due to his health, so not only did we need help and support we also needed financial support. Mum had fractured her spine but had to continue working to make ends meet.

25. We had no help or support as the trouble with not telling anyone is that people do not offer to assist if they do not know the extent of the problem; no one knew to help us, we were isolated. To compound things my Grandad had fallen and broken his hip and was in hospital. My Nan could not help us as she was worried about my Grandad's care, she brought him home. She was right to think this as **GRO-B** **GRO-B** Hospital is now subject to an inquiry into deaths on the same ward and at the same time.

26. I recall when I was at school as part of health and social care, a group came in and did a play for my year group where a woman was infected with HIV through a blood transfusion. At the end they asked would anyone treat the daughter differently and most of my year group said they would; it is inconceivable that I could have told anyone about my situation.

27. When I returned to school after the **GRO-B** holiday I said **SF** had died of cancer as it was more socially acceptable.

28. Up until I was 19 years old it was how all my friends thought he had died. When I was 19 I spoke at **GRO-B** about my experience to campaign for justice. I lost friends as a result, due to the fact they had felt that they had been lied to for years.

29. People say 'oh it has been twenty years so you should have come to terms with it'. I don't think I have moved on from it at all. Still talking about **SF** makes me cry. It has been hard to move on when we have not had justice and no one has been held accountable. Having to fight for justice through campaigning and the various inquiries has meant I am constantly reliving everything. It has made me quite bitter that it has taken so long to get to this stage.

30. Even now over 20 years later there is still stigma associated with HIV and HCV, nothing like when **SF** was alive but I am still careful. After I tell people, the first thing I say is 'don't worry I'm not infected'.

31. I have a complete distrust of the medical profession as a result of my experience. I do not trust them to do a good job and I do not trust them to be honest, nor do I feel safe in hospital. Prior to Covid, I had to attend hospital at **GRO-B** due to a problem with my eye. Once again there was a **GRO-B** in the waiting room and by the time I was seen I was in a complete state and in floods of tears, as a result the doctors dismissed my problem as being stress related, despite the fact I had not been like that prior to coming into the Hospital.

32. Over the past few years, almost every year, in the run up to Christmas, my mum has had to deal with an aspect of the Inquiry such as preparing her evidence or responding to responses from doctors to her evidence. One year to get £10,000 she had to produce **SF**'s death certificate 2 weeks before Christmas, I believe

this was the case for all widows. This has caused her additional distress. I look forward to a point where this can all be put behind us and we can start to heal and try to have Christmas as a happy time like it was before.

33. The way we were treated by the doctors whilst **SF** was dying and after he died has also impacted how I feel about the medical profession. As an example, when my mum was challenging the hospital over **SF**'s death, she was refused a copy of the post-mortem and she had to copy it by hand. This had a damaging effect on her and caused us unnecessary upset. It was simply cruel behaviour.

34. **SF** has not been there for the events in my life like a first boyfriend, going to university, my wedding day. He has also not been there to comfort me through sad times like my recent miscarriage. I have lost having him there to love and support me.

35. He treated me as his daughter, even though he was not my biological dad, he looked after me and he was like my dad. When I was upset or ill he would stay up all night and make sure I was okay. Even the week before he died he took me to the school disco and took me shopping to buy a new dress for it, despite being ill. The way he died is always the first thing I think about and I can't get past it in order to focus on the happy memories. I feel like I didn't just lose **SF** in my future but that the happiness in my past was also stolen from me.

36. The effects of his death and the way he died has had a long-term impact on my mental wellbeing, even over 20 years later. I am still unable to think about the events of that night and when I do think about it, I always try and push it back down as it is too painful to think about.

37. As a result of what has happened and having seen how much my mother has suffered, I am often anxious about anything happening to my husband and being widowed. Having experienced the pain of losing a parent, I worry a lot more about

my family than I would have done otherwise as I am worried about something happening and having to go through it all again.

38. In addition to all the lost time I would have had with SF I have also lost how my mum was before all this happened. My mum has had to spend so long fighting, dedicating more than 20 years to fighting for justice. This has had a huge impact on our lives which cannot be overstated.

39. As I was only a child when SF died, it had a big impact on my childhood as I had to grow up very quickly and very suddenly. I had to take on more responsibility than my peers, as it was now just me and my mother and both of us were having to deal with getting through daily life whilst struggling with grief.

Section 6. Treatment/Care/Support

44. I think once or twice counselling was mentioned but nothing happened. Within the last month I have started counselling through one of the dedicated Trusts.

45. I attended a MacFarlane Trust weekend when I was 16 years old, I think I was offered a counselling session when I was there.

46. I think there should have been a specialist on hand to deal with these issues and help people. Someone who knew all about this situation.

Section 7. Financial Assistance

47. He was registered with the MacFarlane Trust but I do not know what he received.

48. I received a grant of £200 to buy books whilst at university; I do not remember the process. I believe I wrote a letter; I had to prove certain things and I had to get quotes for the books and I only received it for one year.

49. Mum has struggled a lot financially. At one point, I lost my job and had to move back in with my mum. She was receiving a widow's top up payment from the MacFarlane Trust. The MacFarlane Trust deducted the commercial rate of rent for the room I was living in from the payment she was receiving from the MacFarlane Trust even though I was not working and had no income and so was not giving her anything and they knew this.

50. I had to move out as my mum could not afford to have me there. So I had lost SF and then the Macfarlane Trust made it so I could not live with my mum. It was horrible and very upsetting for both of us.

51. Mum had no one to support her financially then, due to the HIV and HCV SF was unable to get life insurance or mortgage protection, therefore when he died, she did not have the safety nets that you would normally have when someone dies.

Section 8. Other Issues

52. I have attended protests since I was 18 and it has felt like this has got us nowhere. Over the years I have felt bitterness to other protest groups that have obtained justice where we have not. This in turn makes me feel guilty for feeling this way as they are also victims. It has been hard to understand how other campaigns have received publicity and access to justice and we have not. It feels as though the Government does not care about us and that those who have died have not been counted.



53. The delays by successive Governments to address the issue of Contaminated Blood and no one having been held accountable, has caused additional damage.

Section 9. Anonymity, disclosure and redaction

54. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed  ...


Dated: 27 October 2022