ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN2079001
Exhibits: WITN2079002
Dated: 29th August 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10th August 2022.

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

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1981, and my address is known to the Inquiry. My partner GRO-B and I have been together for 15 years and we have two children together, our son GRO-B and our daughter GRO-B. I intend to speak about my brother, GRO-B: B, who was born on the GRO-B 1975 and passed away on GRO-B 1992. B was infected with hepatitis C and HIV through Factor VIII treatment for his Haemophilia A. I exhibit my brother's Death Certificate under **WITN2079002**. I will speak in particular about the nature of his illness, how the illness affected him, the treatment he received and the impact it had on his and our lives together as a family.

2. I wish to remain anonymous for this statement.

Section 2: How Affected

3. I was very close to B. He was quite a quiet boy, but he was very good at art and very creative. He was just a really nice person. He loved going to school and was always doing well there, he was intelligent and funny and got on with everyone.

4. B was infected with HIV and hepatitis C as result of receiving Factor VIII as part of his treatment for severe haemophilia A. B was primarily treated at Yorkhill Hospital in Glasgow and would typically receive Factor VIII in response to bleeds. I cannot say exactly when B was infected but I know he contracted those infections through his regular Factor VIII treatment.

5. As far as I am aware, neither B nor my parents were ever informed of the risk of infection from the blood products he received.

6. Due to how young I was at the time; I do not remember exactly when B was diagnosed with HIV or hepatitis C. All I can remember is how quickly his health deteriorated and witnessing him getting really unwell as time went on.

7. I do not know a great deal about what information B and my parents were provided with when he was given his diagnoses. However, from what my parents have told me, my mum was just told about the HIV infection like it was something in passing, like it was matter of fact and something they had to accept and get on with. I don't think there was any kind of support available at the time. I think it was a case of the doctors saying, these are the facts, and then leaving it at that. I don't think B, or my parents were given anywhere near enough information to understand or process his infection. Maybe there wasn't a great deal of information or support available at that time, but regardless my parents did not get the information they needed. I remember my mum was really angry about the way she'd been told, there

was no support, no understanding and no empathy from the hospital at all. The information was given to them so abruptly, I think it was terrible the way my family were treated.

8. I think B could have been told about his infection much earlier than he was. I think the doctors were aware of his infection, I think they knew about it and held off from telling him out of fear. They knew what was going to happen to him and didn't want to face it. I don't think that the doctors wanted to have to tell parents that this had happened to their children under their care. I personally believe that they kept it a secret and they didn't want families to know.

Section 3: Other Infections

9. As far as I am aware, B did not contract any other infections as a result of his haemophilia treatment other than HIV and hepatitis C.

Section 4: Consent

10. As mentioned previously, I was too young to remember anything at the time, but my parents have told me since that they strongly believe B was tested without his knowledge or consent. They talked about how B would regularly have tests done and they would not be informed what exactly they were for. They assumed the doctors must have known but they were never informed about the tests or asked for consent. For example, I do not believe that my parents were informed that B was being tested for HIV or hepatitis C before he was given his diagnoses.

11. I also believe it's possible that B could have been tested for the purposes of research. I think the doctors were aware of the infections before they informed the families and so any testing they did before the diagnosis was given could have been in their own interests.

Section 5: Impact

12. I think because of my age at the time B was dealing with his infections, it was difficult to pick up on how they were impacting him mentally. However, I can only imagine they would have a significant impact on his mental health, it was a hell of a lot deal with at such a young age.

13. What I do remember is that B was always very unwell because of his infections. He was admitted to hospital frequently and I remember as a child going to the hospital to visit him quite a lot. I remember B had to take a lot of time off school as well. He was just very sick and unwell during that time in my life. He lost a lot of weight during that time, and he was much smaller than he should have been at that age. He struggled with coughs and chest infections and dealt with quite a bad case of whooping cough for time. He regularly dealt with nausea and vomiting. I remember he would also pick up quite a lot of infections like colds and flus, and I think that was because the infections had impacted his immune system in some way. He suffered from a lot of health problems really, most of my memories of my brother at that time were of him just being very unwell.

14. I remember that when B passed away, we were told that he had developed measles in the brain, which had been the cause of his death. As far as I am aware this had linked to his HIV infection. That was the major complication that I believe B developed as a result of his infections.

15. B was given medication to treat his HIV, though I cannot remember exactly what it was called. I also am not aware of the period B would have been receiving this treatment. From what my parents have told me, the medication B received was quite invasive and intense. It caused severe weight loss and stunted his growth and development. The treatment just made him very unwell, if being even more unwell was possible. It was meant to be helping him, but it really didn't seem like that. In terms of side effects, I remember the treatment made B very nauseous and he often vomited because of it; It also caused diarrhoea a lot of the time. I really took a toll on

his whole body which made him feel even more unwell, it must have been a miserable life for him, having to live with that.

16. I am not aware of B having faced any difficulties or obstacles in accessing treatment. I do not know if there were alternative treatments that ought to have been made available him. One thing I do know however is that B was treated with different medication for his HIV infection than GRO-B GRO-B, who was also a coinfected haemophiliac. I do not know why B received a different medication, but B went on to pass away and GRO-B went on to survive, so perhaps B could have received different a treatment.

17. I cannot say for sure whether B's infections impacted his treatment for other conditions. I know that because he was a haemophiliac, there would always be extra precautions taken at the dentist for example, in case he had a bleed. I suppose some of those precautions could have been related to his infections as well, it's difficult to know for sure.

18. Before B became really unwell, he had a few good, close friends at school that he used to see quite a lot. As his health deteriorated, he saw them less and less, partly because of the state of his health but also because I don't think he wanted anyone to find out about his infections. His health and his infections really impacted his confidence as a person. He didn't really have much of a social life when he was unwell. Obviously, we all tried to support him as best we could but that was really what his life was, just his family. Being so unwell really limited his ability to do anything physical, so B didn't really do any kind of sports or activities anymore once his infection took hold, which was such a shame. He used to love swimming, surfing, cycling, and walking the dog; he was such an active boy before he became unwell.

19. I think a lot of what happened to B as a result of his infection was kept from me at the time. I was only 11, still in primary school, so I don't think my parents really wanted to put that on me. It wasn't until my early 20s that I was really told what had happened to B. Even though I didn't know

everything when I was younger, I remember having to struggle to get through primary school and high school knowing my brother was so unwell. I knew I didn't understand everything that was going on with B and that impacted me. When he passed away, I was devastated; I remember being so sad, angry, and trying to grieve on top of everything else was quite overwhelming. I did have sometimes where I was dealing with depression and anxiety because of the loss of B. I was so young when he died that I didn't really understand everything that was going on or how to really process that kind of grief. I remember the whole experience of B's decline and his passing took away a lot of my confidence, I was a lot shyer as a person after it all.

20. Knowing what happened to B was something I carried into my adult life when I was having my own children. I am a carrier of haemophilia, and I was so scared that I would pass it on to them and they might have to deal with the kind of horrors that B did. That fear weighed on me for some time.

21. My mum was really impacted significantly by B's passing. She began to drink quite heavily after he died and paired with the amount of grief in the family at the time it made the house quite an intense place to be. Everyone was struggling with it all.

22. Even being quite young at the time, I knew growing up that my family didn't want anyone to know about my brother's health or their infections. There was a real concern that somebody might find out, and so we were told not to talk to anyone about it and that it just wasn't to be talked about in general. I remember always having to think about what you were saying to people and having to be careful when I was talking about my brothers and what happened to them. That really came from the fear of the stigma surrounding the infections. By not talking about it and bottling everything up I was containing my grief and avoiding expressing my emotions which really affected my physical and mental health when I was growing up and into my adult life.

23. My mum blamed herself in some ways for had happened to B. She was essentially his full-time carer when he was unwell so his passing and the decline in his health before it really impacted her quite significantly. It wasn't her fault, but she felt responsible because she had chosen to give her child these infected blood products. Carrying that guilt for so many years meant that my mum eventually started to drink quite a lot, and that was a problem that got worse and worse as time went on. That was her way of coping, just to drink. Mentally, the impact of what happened to B led to my mum having depression, anxiety and feeling a lot of anger. The house became quite an intense environment during those years, there was a lot or arguments between our parents.

24. Due to B's health and its decline, he missed quite a lot school because of the number of appointments and admissions he had. This meant that he was always playing catch up with his schoolwork, but he did try to keep up.

25. I missed some time at school myself when I was younger because I might have had to leave school early so, I could go with my mum and my brothers to appointments for example. I was too young at the time to have gone home myself, so I had to go along. This meant I often had to catch up on the work I had missed. B's death also had quite an impact on my education. I was due to start high school when B died, which is a big thing in any child's life. However, dealing with the death of a sibling and the associated grief meant that starting high school was quite difficult for me to adjust to. B's illness and death were always playing on my mind and sapping my confidence. I think that just meant that I didn't have the same focus that I could have for my studies. I was grieving, and it was just hard to keep going at the same pace. I did okay with my grades, but I know I could have done better. I was unhappy at school through dealing with the grief of losing B, worrying about my mum's increasing drinking and living within the very tense home environment. I was intelligent and capable of achieving more, however my unhappiness and lack of confidence and self-esteem stopped me from pursuing better grades.

26. My mum had to give up work to look after my brother, looking after him full-time. She previously worked in quite a few part-time jobs over the years, she worked as childminder, or in shops or in a pharmacy. But that type of work had to stop when B became ill. This had a financial impact on the family as well because there was less money coming in and it meant that my dad just had to work harder to provide for us.

Section 6: Treatment, Care and Support

27. I am not aware of B facing any obstacles in accessing treatment, care or support. However, I don't remember there being a great deal of support available to him. Everything that he needed was provided at home by my mum and the family.

28. I do not know whether B was ever offered any kind of counselling or psychological support. I think he would've benefitted from it, especially knowing how helpful counselling has been for me in the years since he passed.

29. I have never been offered any kind of counselling or psychological support as a result of what happened to B. I have been offered counselling more recently through my son's hospital. They have a psychologist there to help bleeding disorder patients and their families with any issues they may have. My first session with the psychologist was when my mum died, and I found that very helpful. It was nice to be able to speak to someone who had experience of bleeding disorders and the kind of historic issues that surround them. My sessions with the psychologist are ongoing and I have regular appointments with her every 4-6 weeks. These sessions are very helpful for me in processing everything that happened in the past but also in supporting me with my life now. I think I would have really benefited from this kind of support when B was ill or when he passed. It would have helped to cope with everything a lot better. I do not think that I would be able to cope with everything quite so well now were it not for the support of the psychologist.

Section 7: Financial Assistance

30. I don't believe that B ever received any financial assistance while he was living.

31. I know that the family received a payment of some kind, but I am not sure when this was, how much this was or what organisation made the payment.

Section 8: Other Issues

32. Something I think is extremely important is the impact these infections have on the mental health of everyone involved. Myself, being a carrier of haemophilia, I really struggled with my experiences with B's infections when it came to having my own children. It was really tough having to put those thoughts aside. I even struggled with the decision to have children because of the thought of what had happened to my brothers. When I found out I was having a son it was really concerning to think about him having the same condition as B and potentially being put at that kind of risk. I endured a very stressful pregnancy, constantly worrying about what the future might hold for my son with haemophilia. It is like living in constant fear. We have always been worried about any kind of new treatments they would offer to my son, and it is sometimes hard to take the clinicians assurances because we are reminded every single day of what happened to B. It is only through my sessions with the psychologist that I have learnt ways of coping better with everything.

Statement of Truth

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

Signe GRO-B

Dated Sep 29, 2022