

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN4012001

Exhibits: 0

Dated: April 2020

INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF GRO-B

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

**Section 1. Introduction**

1. My name is GRO-B and I was born on GRO-B I live at GRO-B
2. I am married to GRO-B: H and we have GRO-B I am a GRO-B GRO-B
3. I make this statement as the affected wife of my husband, who was infected with HIV, Hepatitis C and Hepatitis B via contaminated Factor VIII concentrates. He has provided a witness statement to the Inquiry under witness number GRO-B
4. This witness statement has been prepared without the benefit of access to my husband's full medical records.

**Section 2. How Affected**

5. My husband has severe Haemophilia A for which he requires treatment with Factor VIII concentrates. I refer to my husband's witness statement for further information in relation to this section.

**Section 3. Other Infections**

6. I refer to my husband's witness statement.

**Section 4. Consent**

7. I refer to my husband's witness statement.

**Section 5. Impact**

8. I first met [H] in [GRO-B] when I was aged [GRO-B] and he was [GRO-B]. It was my first serious relationship and not long after we started dating I remember being on the receiving end of a barrage of questions from my mum and dad as to how [H] could afford to own a [GRO-B] when he was still so young. I was unable to answer their questions because at this point, I was only aware that [H] was a Haemophiliac.
9. Not long after this and early on in our relationship, [H] disclosed his Hepatitis C status to me. I immediately comprehended the seriousness of what he was telling me but I was very sure of my feelings for him; I loved him so much by this point that it would not have mattered what he had told me. However, I remember being extremely emotional trying to process and deal with the enormity of what he had told me and what this would mean for us in the future. This all coincided with my A-Levels. I remember crying a lot of the time which led to further questions from my mum and dad.

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10. Therefore, with [H] approval I told them that [H] had Hepatitis C. They were, of course, concerned for me but by this time they already loved [H] to bits and they knew that I adored him. They asked me how I felt about the news and whether I would be strong enough to deal with things, if and when [H] health substantially deteriorated. I thought that [H] and I were strong enough as a unit to deal with whatever further issues life decided to throw at us. I was never going to leave him but I did really want children and that was the one thing that [H] was saying that he was unsure about because he felt that it may not be possible due to his Hepatitis C.
11. I remember my friends questioning me at college as to why I was always so emotional and often in tears. I was not able to tell them the reason why I was upset because [H] did not want me to disclose his Hepatitis C status to anyone else (except my parents), due to the stigma surrounding the same. Unfortunately, this did cause a degree of uneasiness between my friends and me as I think they thought (rightly) that I was keeping something from them and I was acutely aware that this was the case.
12. Up until this time, I was only aware that [H] had Hepatitis C. It was not until I completed my A-Levels that he dropped the "bombshell" that he was also infected with HIV. There was no doubt in my mind that I wanted to support him but I felt like I had just embarked upon another emotional rollercoaster. I think that [H] and I matured much earlier than we would otherwise have done as a result of trying to both process and deal with his infections, albeit at slightly different times.
13. [H] family ended up supporting my family because they were also being affected by what had happened to [H]. Ultimately, we all supported each other and we had, and still do have, a very close knit family circle. The nature of [H] infections meant that we could not disclose their existence to anyone outside of our close knit circle for fear of stigma. By this time [H] had become good friends with my [GRO-B] so we made the decision that he would also need to be told about [H] infections. Then when [GRO-B] met his future wife-to-be, issues arose as to whether she should

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be told. [GRO-B] was of the view that she was extremely understanding and should be told whereas initially [H] expressed a more cautious approach and was reluctant for her to know. In the end, the decision was made to tell her. However, further issues arose as to who should divulge the news to her; [GRO-B] wanted to do it but [H] felt that it was his news and therefore he should be the one to tell her. In the end [GRO-B] briefly mentioned to his wife that there was something that [H] had to tell her but it was [H] who sat her down and explained the full extent of the conditions and infections he had contracted.

14. I remember going off to university and being extremely worried because this coincided with [H] contracting [GRO-B] which led to a period of hospitalisation. Embarking upon university life is meant to be a carefree time where one can escape any worries and just go and have fun. I was, however, deeply worried about [H] health and I remember going to visit him in hospital with my friends; who had no idea that his infections had rendered him susceptible to [GRO-B]. I felt a little detached from my friends and almost as if I was "*living a lie*" because I was keeping things from my close friends, which was not something that I would have ordinarily done. However, I was only doing it to protect [H]. I do think that my friends would have been able to deal with the truth and would have been both supportive and compassionate. However, we could not take that risk because some of my friends knew some of [H] friends and it would only be a matter of time before someone "*let the cat out of the bag*" and it would not have been fair to have saddled my friends with the responsibility of keeping such a secret. This is going to sound really terrible but I am not sure whether some of [H] "*laddie friends*" would have been so understanding had they found out about [H] infections which would have put him at a real risk of experiencing stigma.

15. [H] suffers with serious depression and mood swings and I spend a considerable amount of time trying to keep his mood buoyant and positive. Having our [GRO-B] was the best thing that could have happened to us but

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because we chose **GRO-B** we faced a further barrage of questions from our friends as to why we had taken this route. It is difficult harbouring this secret and knowing that you cannot be completely frank with people as to the reasons behind the choices we made. Even today, I constantly worry that I may accidentally disclose something connected to **H** health that would give the game away. I feel like I always carry this secret with me.

16. Another effect of **H** infections meant that I developed a phobia of needles. I was therefore fearful of undergoing the **GRO-B** because of this and I had to overcome this phobia during the **GRO-B**

17. When we were meant to be celebrating the **GRO-B** **H** was diagnosed with cancer. It seems to be the case that whenever life gives us something lovely to celebrate, it always has to come with something negative. The cancer diagnosis presented its own challenges and created further worry on top of everything else that we were dealing with and sadly it detracted from the extreme happiness that we should have been experiencing as our **GRO-B** **GRO-B**

18. I think that the main impact on me has been the constant worry about **H** health. I remember it being particularly stressful when he was refused treatment for his Hepatitis C due to not fitting the eligibility criteria. The time that we had to wait and all the information that was given to **H** in relation to not fitting the eligibility criteria, made me feel very anxious, frustrated, uneasy and very let down by the system that had infected him. It also made me worry due to the uncertainty of it all, how **H** would cope mentally and how his body would react physically to the treatment (if and when) he became eligible.

19. It was like having a carrot dangled in front of you and then taken away; the small glimmer of hope that you had is snuffed out. Then the worry sets in again as to the untold damage the infections are doing to his body.

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20. In terms of the HIV continuous medication [H] had to be very responsible in remembering to take his medication every day but I also feel that I need to closely monitor his medication situation just to ensure that he does not miss a dose. The medication, if not taken at the correct time, does make [H] feel very unwell with dizziness and slight sickness.

21. Despite the constant worry, I do believe that I probably end up blanking things out in order to survive on a day-to-day basis without becoming a complete nervous wreck. However, sometimes difficult thoughts do end up running around my head leading to severe migraines.

22. [H] is a fantastic father but due to his arthritis and various conditions, he finds it hard to [GRO-B] without suffering severe reactions and pain in his body the next day; this is emotionally difficult for both of us. Things like this are hard but we always try to make the best of any given situation. The [GRO-B] are a blessing and we try to plan little holidays throughout the year so we have something to look forward to. However, sometimes [H] says "Let's go to [wherever]" and I think "oh, goodness I don't really want to go but he really needs to go away for his mental health". We end up going and having a great time. My moto is definitely developing into one of "live for today". We are so fortunate and lucky to have what we do have in life and I am forever grateful for that.

23. It probably sounds a bit silly but I have to think and plan ahead whenever we go out as a family. [H] does as much as he can but his health certainly both dictates and limits what he can and can't do. I also try to ensure that I always provide [H] with good quality food and a well balanced diet because I want to ensure that he is as healthy as he can possibly be in order that he is in the best possible place to deal with these terrible infections and resultant conditions.

24. I was working full time as a [GRO-B]  
[GRO-B] and [GRO-B] I returned to work on a part time basis. Due to [H] health he was [GRO-B]

and we wanted to enjoy and **GRO-B** and therefore the part time option worked well for us. It also allowed me to devote more time to caring for **H**. I am very organised with my work, often also working at night, to ensure that I can spend as much quality time with my family as possible.

25. I know that **H** is quite tough and that he dealt with so many unimaginable and difficult issues as a result of his infections when he was a child. This is something that no child should have to worry about and when I think about his childhood I become very sad and emotional. **H** has developed such a positive outlook on life, despite everything he has had to deal with on top of his Haemophilia. I am sure that it is this positivity, combined with his sense of humour, which has got him through some very difficult times.

26. I also worry for our **GRO-B** in the future. I know that people's attitudes have changed for the better but sadly stigma does still exist. The **GRO-B** will have questions when they **GRO-B** which **H** and I will have to deal with in both a timely and sensitive manner. The **GRO-B** will then make life-long friends and go on to have partners and decisions will be made by them, as to whom and how they divulge the existence of their father's infections.

27. In my role as a **GRO-B** I am not sure that all of my **GRO-B** would be best pleased if they knew about **H** infections and it is likely that they would want to ask a number of questions to put their minds at ease. I totally understand this as I would be the same if I were in their shoes.

28. This is going to sound awful, but it was a relief when **H** was diagnosed with cancer because it was something we could openly disclose to people without fear of reprisal. Sadly, **H** and I should have been able to tell people about his infections in exactly the same manner as we could with the cancer and to receive the same sympathetic and understanding reaction.

29. Even today, it is still only our close knit family circle who are privy to H infections. My mother is getting older and more forgetful and I worry that she may now accidentally disclose the information to one of her friends. My mother's friends are made up of my friend's mothers and therefore one slip of the tongue could lead to serious repercussions.

### **Section 6. Treatment/care/support**

30. I refer to my husband's witness statement.

31. Although I have never been offered formal counselling I was always made to feel welcome by the nurses when I went to the Haemophilia Centre at the GRO-B in GRO-B with H. If I ever needed to speak to someone they always made time for me. Now, if H and I ever feel a bit low we take a box of chocolates and pay a visit to the nurses. When H was undergoing his cancer treatment in the Oncology Department we would always drop into the Haemophilia Centre to keep in touch with the nurses. I would class their support as "*informal counselling*".

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

32. I refer to my husband's witness statement.

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

33. I want answers for H. I want to know exactly what happened and to what extent he has been lied to by the UK Government. Those responsible for this tragedy need to hold their hands up and compensation should follow.

34. We are enjoying our life as much as we can now and no amount of answers or money can repair the mental and physical damage which H has suffered.

Anonymity

35. I wish to apply for anonymity and I do want to give oral evidence to the Inquiry.

**Statement of Truth**

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

Signed..

GRO-B

Dated..

27/4/20