

ANONYMOUS

Witness Name

GRO-B

Statement No: WITN7438001

Exhibits:0

Dated: November 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

GRO-B

GRO-B

will say as follows: -

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B I live at GRO-B
GRO-B
2. I make this statement in connection with my husband, GRO-B: H
who was born on GRO-B and was infected with Human
Immunodeficiency Virus (HIV), Hepatitis B (HBV/Hep B) and Hepatitis C
(HCV/Hep C) via contaminated Factor VIII concentrates. He provided an
anonymous witness statement to the Inquiry under GRO-B
3. This witness statement has been prepared without the benefit of access to
H full medical records.

Section 2. How Affected

4. I first met my now husband [H] when I was 18 years old and at that point had no idea of his medical condition.

5. It wasn't until our relationship became serious that he told me that he was a Haemophiliac, I had no idea at this point what this condition was or what it entailed. He also went on to tell me that he also was HIV positive. I guess I was young and naïve and didn't really understand the impact of what he was telling me. It was a difficult situation as his parents didn't truly understand what it all meant and I actually remember them saying to me, he was told he had 2 years to live and he's still here so there's nothing to worry about (complete denial or just not informed enough; I'm not sure). But I decided whatever was ahead of us we would encounter it together, which is what we have done. [GRO-B]
[GRO-B]

6. I have supported and nursed [H] through his low times when he contracted [GRO-B] and [GRO-B]

7. [H] and I have dealt with the impact both mentally and physically together that his medical conditions have brought.

8. [H] has Haemophilia A and is classed as severe, having less than 1% clotting factor in his blood. It's hard to pinpoint exactly when [H] was infected with HIV through Factor VIII, although it was in the early 80's [H] was infected through receiving Factor VIII which was manufactured by Armour.

9. [H] suffered severely with what he was led to believe was Hepatitis B in his teens, however, we have recently learnt that it was non-A/B Hepatitis, and this is what Hepatitis C was recorded as before its official diagnosis.

10. [H] moved from the area where he grew up owing to the stigma in the early 80's/90's around HIV and peoples' fear that he could infect them just by touch.

ANONYMOUS

It was when he moved to this area that he met me, therefore I was not there when he was told of his infection.

11. However, I understand from [H] that he was told on his own in a corridor by his then Haemophilia Doctor and was told that he had two years to live at St Thomas' hospital.
12. It is only since he moved to this area when he was 22 years old that I have attended appointments with him and have been involved in his treatment and consultations.
13. [H] became infected before I knew him, however it is thought that he became infected when he was being treated with Factor VIII for a bleed that he was suffering in his leg at St Thomas' Hospital. The injury required him to be hospitalised for some time, owing to the amount of treatment he required there was a concern that he may never walk again, but somehow, he pulled through and with physiotherapy walked again.
14. [H] is co-infected; he has HIV and has cleared Hep B and Hep C. He now suffers with [GRO-B] and [GRO-B] both of which are attributed to his infections and their side effects.
15. [H] has had approximately 21 operations on his anal area owing to a fistula relating to suffering with [GRO-B] and each time he is operated on he is the last to go down to the operating theatre in order that he does not infect others and he has to do a pre and post levels for his Factor VIII so has to make sure his Haemophilia nurse is aware of any operations he needs so they can be around to monitor his Factor VIII levels.
16. Owing to the nature of [H] operations on his tail end, he requires frequent dressings to be changed, which I did for him as he was only receiving one call a day from a district nurse. I was shown by the nurse what to do, so that I could do it for him throughout the day (going above and beyond my marriage vows!!).

ANONYMOUS

17. [H] arthritis causes him issues with his mobility (walking) and his hands (dexterity).

18. Even now, owing to the medication he is on for HIV there is no suitable treatment that he can be given to alleviate the pain he suffers with his arthritic joints. He attends the Arthritis appointments at the hospital, but the consultant doesn't really know what to say or offer him owing to the complexity of his conditions.

19. Neither [H] or his family received enough information or guidance from the medical profession when he was first diagnosed.

20. It has only been very recently that support has become available, so that is helpful for both [H] and me. Especially for [H] as he has been recently diagnosed with PTSD.

Section 3. Other Infections

21. [H] has received letters from all the hospitals where he has received treatment advising him that he may have been exposed to variant CJD.

Section 4. Consent

22. I do believe that [H] was tested without his knowledge, he recalls many vials of blood being taken from him at a time. He doesn't recall ever being told what/why his blood was being taken. He believes that some of his blood was stored and used for research.

Section 5. Impact of the Infection

23. [H] has Haemophilia which has never stopped him from doing anything.

ANONYMOUS

24. However, the side effect from his HIV/HCV/HBV infections has caused him many issues, both mentally and physically. All of which he has been infected with through the use of Factor VIII.
25. The HIV, owing to its stigma stops him from having friendships where he can be open and honest, he and I are always guarded about what we say, especially having sons and the need to protect them from everything.
26. The side-effects of one of the treatments that he was taking for his HIV caused him to have regular nightmare/dreams, he would hit out at me and even wet the bed. Both of which made him feel absolutely ashamed of himself, however it was not something that he had control of, it was the drug he was taking. It was changed and he is more settled now and I can sleep with both eyes closed now!!!
27. The arthritis that he suffers causes stiffness in his hands and makes it difficult for him to grip small things and is unable to make a fist some days. He also suffers with stiffness in his ankles and suffers pain in his lower back. All of which are debilitating for a young man with a young grandson who just wants Grandad to sit on the floor and play or carry him when out.
28. The whole scenario of becoming infected, having to move from the area that he grew up in and away from his family has impacted him mentally; he has had to make a life on his own.
29. We as a couple have been very selective who we have entrusted with H medical conditions and are very guarded about forming friendships; we tend to keep ourselves to ourselves. We also do this presently owing to COVID and H being one of the clinically vulnerable. We are very lucky that our family is close, and we see them very regularly otherwise we could become very lonely and depressed.

ANONYMOUS

30. Our grandson is our life, and we are lucky enough to be looking forward to a second grandchild being born early next year.
31. asks himself most days "*why am I still here, when others have passed*" and never in his wildest dreams did he ever think after being told of his infection that he would marry, have sons, see his eldest son marry and become a father, making him a grandfather and throughout all of this he suffers with survivor's guilt.
32. It is very hard at times to watch what goes through, especially with dealing with all his medical conditions, which have meant that is no longer able to work, losing his purpose in life and having to busy himself with jobs about the house.
33. finds it very hard to trust anyone or anything that he is being told, owing to the way in which he has been treated by the NHS.
34. I am very protective of him and my sons and will stand up and protect them all whatever.
35. I worry what will happen if passes before me and how our sons will deal with the knowledge of their father's medical conditions.
36. Both and I took the decision when they were young not to tell them of their dads' medical condition/infections. This was in the early nineties when the stigma and lack of knowledge/understanding was prevalent. I have always said that when the time is right, I will be the one that tells them and hope that they understand the reason behind our decision.
37. When I had our first son, I was placed in a side room on my own and made to feel like I was a leper, I wasn't able to socialise with the other mothers, which would have been really helpful being a young first-time mum.
38. I have also experienced stigma at the dentist.

39. There have been times in the workplace, not so much now, but in the nineties when people have joked about infecting you with HIV!!!, which of course I didn't find funny but couldn't engage, I would just walk away.
40. To protect [H] and my family, I have not formed friendships where you feel that you can tell them anything. I have one 'best' friend that both [H] and I have confided in, and she and her husband are our rock.
41. When [H] was struck with [GRO-B] and was in hospital for many weeks, I was working and had to take time off work with stress to be able to look after our sons, one of which was in his last year at school sitting his exams whilst [H] was in hospital, it was like I was a single parent, holding it altogether by a thread. I was being strong for both [H] to give him hope and for our sons to give them as normal a life as possible through that difficult time. I would visit [H] twice a day, I would go in and take him to the bathroom and wash him and in the evening, I would visit again bringing our sons with me. I look back now and don't know how I did it.

Section 6. Treatment/care/support

42. There have been occasions when budget has been put in front of what is best for [H]. Recently [H] retroviral drug was changed for a cheaper one which didn't agree with him, and he and I had to really fight to get him put back on the drug he was using originally (he now has special dispensation from the local authority to have this drug). He should never have been in this position, especially as he is suffering through absolutely no fault of his own.
43. Only very recently has counselling been offered to [H] which he has taken up and receives weekly counselling which is helping him. He struggles with what the Inquiry unfolds daily and the wrong doings that have been done to him and others like him and suffers survivors' guilt.

44 [H] listens to the Inquiry daily and listens to Jason Evans' podcasts, although I am truly truly empathetic to their situations, I can't invest the time that [H] does to it all. I work and have to concentrate on that and also keep our home life going. I think if I was to allow myself to become embroiled in as deeply as [H] I would become very very deeply depressed and very very angry for their situations. I don't mean to sound selfish, but this is how I cope.

Section 7. Financial Assistance

45 [H] and I have been part of the past litigations and did receive an award from the government. I do recall being told by the solicitor that was dealing with our case that if we didn't sign the waiver then none of the others would get their awards, it was all or nothing. I was pregnant at the time with our first son.

46 [H] receives a monthly income from the EIBSS.

47 [H] initially had his claim for Hep C rejected, I think it took three appeals to get it finally agreed, although it was clear that he had been infected.

48. We have been pretty lucky enough not to have to ask for any financial assistance. I can recall perhaps three occasions where we approached the MacFarlane Trust (MFT) at the time and had no trouble with being awarded what we were asking for.

Section 8. Other Issues

49 [H] has extensive medical notes available that I can draw upon if required.

Anonymity

ANONYMOUS

50. I am more than happy to submit this witness statement; however, I wish to remain anonymous and where appropriate for any personal information to be redacted.

Statement of Truth

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

GRO-B

Signed.....

9th November 2022

Dated.....