Witness Name: GRO-B
Statement No.: WITN3324001
Exhibits: None
Dated: 17 November 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF
GRO-B

Section 1. Introduction

1. I, GRO-B will state as follows: -

2. My date of birth and address are known to the Inquiry. I live with my wife and three children in GRO-B and I work for the NHS.

3. My wife, GRO-B: Wife has also prepared a witness statement for the Inquiry. I have read her statement and agree

with the contents. I make this statement to add any facts to the history.

Section 2. How Affected

4. I met GRO-B: W in 2007 and we married in 2011. I have therefore known her for over 12 years.

5. My wife believes she was infected with Hepatitis C (HCV) as a result of blood transfusions she received as a very young child. She was only diagnosed with HCV in 2018, when she was 33 years old.

6. GRO-B: W was diagnosed as follows. She was suffering with abdominal pain in 2018 and was having tests to investigate this. She received some results and was told it wasn't cancer, which was a great relief as that had been her main concern. However, the Advanced Nurse Practitioner (ANP) asked to see her, so we thought it was some sort of follow-up appointment. It was for this reason that we didn't think it necessary for me to attend the appointment with her, so she attended alone.

7. I was at work at the time of her appointment and she called me in the afternoon. She told me she had been diagnosed with HCV and sounded very shocked.

8. My wife and I usually see the same ANP and he is very, very good. I understand that he would not have wanted to scare

her, however, I was disappointed that he didn't tell GRO-B: W he was testing her for HCV. This meant she had no opportunity to prepare for such a diagnosis. I would also have liked to have been present at the appointment with her, rather than her having been alone to receive this diagnosis.

9. As soon as we finished speaking on the phone I searched online for HCV and found the Hepatitis C Trust and rang them immediately to find out what I could. The person I spoke to at the Trust had been infected herself and was very helpful. She sent us a lot of information. I have spoken with the Trust regularly since GRO-B: W was diagnosed, particularly through her treatment, and their support has been invaluable.

10. After GRO-B: W was diagnosed, we were advised that both me and the children ought to be tested for HCV. It was a worrying time waiting for the children's results but thankfully they came back quickly and were negative.

11. As for me, there were some awkward questions from the doctor about whether I had used drugs or had sex with prostitutes. It was upsetting to go through this, and I know my wife in particular was very upset that I was questioned in this way.

12. The ANP was clearly shocked at the diagnosis because GRO-B: W had no risk factors, other than the blood transfusions. The ANP couldn't understand how she had not been diagnosed before, given her medical history. I am also

surprised that the diagnosis was not picked up earlier because GRO-B: W has had multiple operations throughout her life, very frequent hospital attendances and, before diagnosis, she had had two children.

13. I understand that her medical records show abnormal liver results for many years prior to diagnosis. These results are set out in her statement. I know that her medical history is complex, but I still believe these results ought to have led to some form of investigation which might have led to earlier diagnosis with HCV.

Section 3. Other Infections

14. I do not believe that my wife received any infection or infections other than HCV as a result of being given infected blood products.

Section 4. Consent

15. As I have described above, I believe the ANP we saw ought to have told my wife that she was being tested for HCV at the time of the blood tests and obtained her consent for this. I have followed the Inquiry very carefully and am surprised that testing without consent is still happening, as recently as 2018.

Section 5. Impact

16. Physically, the diagnosis of HCV made sense as, in the years leading up to her diagnosis, I became increasingly worried about her due to her levels of fatigue and suspected that she may have ME, or something similar. She became so tired she would fall asleep in the daytime.

17. The mental effects of the diagnosis on my wife are hard to describe as her diagnosis was relatively recent. She has not wanted to talk about it very much. I think she worries about the future and what will happen. She was not ready for counselling when she was first diagnosed, but I think she may be now and will probably do this.

18. For me, I was very shocked when we found out. Trying to understand how someone has suffered from an illness for over 30 years without knowing is hard. I think I am probably still trying to process this.

19. I have always worried about her because of her other health issues, which I knew of when we first met. But this is something new and more unknown. I worry about the future and how this will affect her life expectancy: no one knows what has happened inside her body, how this disease has already damaged her organs, what sort of toll has it had on her body. I wonder whether there will there be a resurgence when she is older. It is always in the back of my mind.

20. I am the sort of person who reads up on things to ensure I understand everything I can about something. I have done that with HCV and have also followed the Inquiry's progress. My wife does not follow the Inquiry too closely because she finds it difficult to cope with, so I tend to summarise things for her, though I find the stories of the infected and affected very upsetting at times because of the way people have been treated during the course of this scandal.

21. In terms of treatment, we spoke with the Hepatitis C Trust about the options available, and that was helpful. However, my wife was never given the opportunity to see a consultant as all her treatment was managed by her liver nurse. Though this care was very good, I think we would have benefitted from seeing a consultant, and this was also relevant to my wife's EIBSS application (see below).

22. At the time of treatment, I was very frustrated that my wife was repeatedly told how costly the treatment was. Although I can understand clinicians' concerns about costly treatments, this should have no impact or bearing on my wife's care and it was inappropriate to tell her about it. She should certainly not be made to feel guilty about it, particularly at a time when she was still coming to terms with the diagnosis. She was infected with this terrible virus as very young child as a result of being given contaminated blood and needs the treatment, regardless of the cost.

23. This burden of knowing how costly the treatment was created the additional fear of what would happen if the treatment did not work. We knew little about other options if the treatment failed, and this was a constant worry during the course of treatment. Thankfully, the treatment succeeded in clearing the virus.

24. GRO-B: W suffered a lot with the physical side effects of treatment. She was very itchy and suffered with skin loss. It was not very pleasant for her, but we knew it would only be temporary. Mentally, I know that she felt very down after diagnosis, and became really depressed. I think this was partly due to the diagnosis, but also perhaps a side effect of the treatment. The positive thing for her was that she knew she was getting the treatment, and she looked forward to the blood tests to check her viral load was decreasing. She used the blood tests to help get her through the treatment.

25. Although we are of course delighted that the treatment cleared the virus, I do feel that GRO-B: W ought to have been offered an ultrasound scan. She had a fibroscan before treatment started but has never had an ultrasound. I think it would have been more reassuring to us both to have had more investigation of her liver, rather than relying only on the liver nurse telling us that the fibroscan results looked ok. I believe GRO-B: W should have been offered an ultrasound already, and also by way of regular follow-up.

26. I do not think that GRO-B: W infected status has impacted too greatly on her treatment for any other conditions, however, for her, I think it probably feels like yet another label. She already has to explain so much to others about her health conditions and now she has to add this too. There are 'standard precautions' in the NHS for infection control, so people should not really have to explain about this sort of infection, but GRO-B: W does so anyway, just to be careful. I know she feels bad having to mention it and I think this is because, although no one asks how you became infected, you know that they might be wondering about it and asking themselves whether she is a drug user or a prostitute. I hope a change in attitudes is brought about by this Inquiry in this respect.

27. The impact of the diagnosis led to a tough time for us as a couple both at the time of diagnosis and during subsequent treatment. Writing this statement and keeping up with the work of the Inquiry keeps things fresh and I think that is probably one of the hardest things, as it keeps bringing things back to the surface. I think that is why my wife finds it very difficult to watch the Inquiry, so I do a lot of reading and watching for her and then give her an update.

28. The diagnosis has not impacted too much on our children as they are still very young, and we have not told them anything about it. If we find it still impacting on us as they grow older, we may need to consider telling them about the virus, but at the moment we don't want to worry them unnecessarily.

29. We have told very few people about the virus, but we have told our immediate families. This was very shocking for GRO-B: Ws parents as they spent so much time in hospital with her when she was a child and couldn't believe it had not been detected earlier.

30. There has not been too much of a social impact as we have not told many people in our social circle at all. However, this does mean that GRO-B: W has to find ways of explaining why she does not drink alcohol any more, and she is very careful about what she eats as she knows it is the liver which has to process everything. She always has her liver health at the back of her mind, as she does not know what damage might have been done.

31. There is still so much stigma around the disease that it does not feel possible to be really honest about it. I was surprised at the reaction of some of our close family when we told them, as one member of our family asked when she had used drugs. We don't share my wife's status unless we have to. Sometimes I worry about how I would explain things if GRO-B: W became ill as a result of the HCV because no one knows about it in our wider social group.

32. I think the virus had an impact on GRO-B: W before diagnosis and has affected her education. She was doing an English degree at university and, though she was really good at English, she struggled and did not complete her degree. I had to help her

with an essay once because she simply couldn't do it. This was unusual for her and at the time I just thought she was really tired. Looking back, I wonder whether she was struggling with brain fog. I now believe that the HCV was affecting her energy levels and ability to focus and function. She also had really bad itchiness at the time and perhaps that was due to a high viral load, as I am aware that itchiness can be related to liver problems.

Section 6. Treatment/Care/Support

33. My wife did experience a four month delay in obtaining treatment as her genotype had to be established and funding obtained. As I have described above, it was the fact she was told how much treatment would cost that I felt was entirely inappropriate.

34. Counselling and psychological support was offered to GRO-B: W but I think at the time it was offered it was too soon for her. I think she would now be ready to take up an offer of counselling. I was not offered counselling or psychological support at the time of diagnosis. However, very recently, EIBSS contacted us to offer £500 towards the cost of private counselling. I think this is something we will take up and wonder whether this offer comes as a result of the work of the Inquiry.

Section 7. Financial Assistance

35. My wife has been granted financial assistance through EIBSS but, as I have mentioned above, there were difficulties as she did not have a consultant and the forms require a doctor to complete certain sections. As we had never seen a doctor, there was a delay in getting the forms completed.

36. GRO-B: W had to obtain her medical records to find evidence of the blood transfusions before she could apply for financial assistance. I feel we were very lucky to have managed to obtain her medical records from 1984 and 1985 as I have now heard so many accounts, through the Inquiry, of people struggling to find their medical records. It does not seem to be a particularly fair system.

37. For our family, the financial support from EIBSS has been very helpful. The extra money has meant I have been able to go part-time, to help my wife. She is a full-time mum and whilst this is hard enough on its own, the HCV means it is even more difficult as she still gets very tired. Being part-time works really well for us as I can help out at home for two days of the working week. We are also able to afford to put our children into a little bit more childcare, which again makes things a little easier for GRO-B: W. The money doesn't cover everything, but it offers us a little more flexibility, security and rest for my wife.

38. Strangely, I experienced some criticism for being male and going part-time – from family, friends and work colleagues. I felt unable to explain I had done this because of GRO-B: W HCV, due to the stigma of the infection.

39. I think the EIBSS scheme could be improved with regular, detailed updates. We also need to know that financial assistance is for life. At the moment there is no sense of security, as the payments could end at any time.

Section 8. Other Issues

40. I hope the Inquiry will achieve the following:

41. That there is an apology;

42. That people are held to account for both what happened at the time and what has been happening since that time;

43. That recommendations will be made to ensure that those infected and affected are looked after for the rest of their lives, both from a healthcare perspective, with some form of priority access to the NHS such as that given to veterans and cancer patients, but also with financial support from EIBSS being guaranteed;

44. That public awareness of the scandal heightens;

45. That screening is offered to everyone at risk (for example, all those who had surgery in the 1970s, 1980s and 1990s and their loved ones who might be at risk of transmission); and

46. That the Inquiry's recommendations are implemented by the government in full.

Statement of Truth

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

Signed GRO-C ....

Dated 17/11/2020