ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN3196001
Exhibits: None
Dated: September 2021

Infected Blood Inquiry

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 GRO-B 1985. I reside at GRO-B

2. I live at home with my husband, GRO-B: H and our seven-year-old daughter, GRO-B . H and I met at GRO-B University in 2003 and we got married or GRO-B GRO-B . I have been employed as a teacher for around eight years and I teach year one children at primary school. I love being a mother and enjoy socialising with friends and going to the cinema when I can.

Section 2: How Affected

3. H was diagnosed with severe haemophilia B and contracted Hepatitis C from contaminated blood products provided to him by the NHS as a child. H was officially diagnosed with Hepatitis C in 1993 when he was nine years old.

4. I am aware from H and his mother GRO-B, that H was initially under the care of Lincoln County Hospital ("Lincoln") for the care of his haemophilia treatment. However, he moved his care to Sheffield Teaching Hospital ("Sheffield") to be under the care of Dr Makris in around 2002, which was around the time I met him in 2003.

5. H and GRO-B have provided separate statements to the Inquiry (WITN0383001 and WITN1050001 respectively) which discuss H's childhood in more detail. I understand that GRO-B statement to the Inquiry discusses which blood products H was given as a child and H's statement discusses the impact on him. In this statement I will focus on the impact that H's Hepatitis C has had on our family, from when I met H in 2003.

Section 3: Other Infections

6. I understand from H that at the time H was diagnosed with Hepatitis C in 1993, it was confirmed that he had not contracted HIV.

7. H also contracted MRSA whilst undergoing treatment at Sheffield Hospital, H managed to clear these bacterial infections.

8. In April 2000 H received a call from Dr Adelman at Lincoln about possible exposure to Variant Creutzfeldt-Jakob disease ("vCJD"). H told me about the call and that he was only been told that he might have been exposed to vCJD. H also had to check all the bottles of Factor IX he had stored at home to see if he had any infected batches that needed to be tested. I believe he must have been given specific numbers to look for on the bottles. This was worrying and stressful news for the family.

Section 4: Consent

9. As mentioned above, H was diagnosed with Hepatitis C as a child. He has told me he does not recall being tested for any viruses as a result of receiving contaminated blood products, but his mother stated that they had tested him without her approval in 1991. H and I have both been informed by H that he was tested for both HIV and Hepatitis C and was given the results around 1993. GRO-B has provided more information about this in her statement to the Inquiry.

10. I am not aware of any issues in relation to H consenting to the treatment for his Hepatitis C prior to me meeting him.

Section 5: Impact

Impact of H treatment

11. I am aware that H had undertaken one treatment course to clear the Hepatitis C virus when he was a child and before I knew him, and this first treatment is discussed in more detail in H and H statements to the Inquiry.

12. I met H at GRO-B University in 2003, which was around the time he started his second treatment for his Hepatitis C. I am aware that this treatment course consisted of Interferon and Ribravirin which was a mix, and that the Interferon was administered by way of an injection into his stomach. H really hated administering this treatment because it made him quite sick. It was not easy to administer and he had to be careful when treating.

13. I witnessed the side effects that this treatment had on H. This treatment made H lethargic and lacked any effort to be awake, carry out daily routines like washing and prepping food. I believe that it probably affected his studies as he was unable to focus his energy for long periods of time, his sleep pattern was all over the place and he felt really deflated which I saw in his demeanour. H struggled to motivate himself to study and struggled with his second-year exams, which resulted in him changing course from aerospace to sport to

see if this would better support his current mood, state of mind and health in general.

14. The worst times H and I have had together were when H was on this second treatment to clear the Hepatitis C virus and the resulting aftermath. There were the obvious fears of H not being able to complete the treatment, but there were also difficulties dealing with his personality changes as a result of the medication. At one point H became really depressed and started having suicidal thoughts. On many occasions I would have a phone call from him when he felt really low and deflated and wanted it to end. He would cry out in pain from the injections. It was terrible for me to witness him changing and realistically hurting himself to try to get better. This was a really difficult time for us, especially being so young and just dating.

15. Despite everything H went through and all of the side effects he experienced unfortunately, the second treatment course did not clear his Hepatitis C.

16. On one particular occasion in 2006 H s mood really plummeted and he attempted to hurt me. He pinned me up against the wall, for no reason and started screaming at me. I was really scared and quite emotional. This was completely out of character for H as his usual temperament is calm, laid back and very easy going- not hot headed in the least. It really tested my boundaries. However, I knew what H was really like and I remember saying to him that he needed to go to the doctor so that it could be investigated and I could not live like this if it continued. I decided to stay with H and be as supportive as I could as I love him but it was really challenging for quite a few weeks as I was nervous, he could just turn like that again. I have done a lot of reading in order to be as educated as I can about both Haemophilia and Hepatitis C. Unfortunately, H did not receive any answers or support as a result of those investigations with the GP or for counselling. We sourced some online therapies to support at home and encouraged the writing of a journal for his emotions but he lacked the energy to carry this out regularly.

17. H did not receive any further treatment until around 2016, when he underwent the third treatment to clear the virus. This was a combination Viekirax and Exviera and this had to be taken as a tablet form over a 12-week course.

18. I remember H was elated after finding out that this treatment would be taken as a tablet. He really hated the second treatment, particularly because it had to be administered as an injection. Even though this sounded more positive, I was still cautious and wanted more information about the potential side effects of the treatment, given how H had reacted to the second treatment. I also doubted that the treatment would work as it was only tablets, rather than an injection.

19. As part of this third treatment course, H was given a diary to record notes and had access to a counsellor over the telephone. This made a huge difference to H and helped to keep him motivated to carry on with the treatment. He had to have regular blood tests and liver function tests to monitor the success of the treatment. He kept a record of his viral load in the diary given to him, which showed the effectiveness of the drug:

    a. 01 November 2016 – 28,882,410
    b. 23 December 2016 – 11,800,010
    c. 26 January 2017 – 108
    d. 28 February 2017 – no trace

20. Thankfully the treatment worked and at the end of the treatment course there was no trace of H's Hepatitis C virus. Whilst we were elated, it was still nerve wracking as we were told that there could be a recurrence of the virus within the following three months. H had to be tested for those three months to make sure that the virus had not returned, before the doctors could confirm H was clear of the virus.

21. I did worry a lot during this time, wondering what we would do if the Hepatitis C came back and the treatment did not work permanently. You play games with

yourself in your head just thinking about what you would do next. It was a tough time as we wanted to celebrate and move our lives forward and yet we were still in a limbo.

22. [redacted]s overall experience of this third treatment was a lot more positive than the previous treatment courses he underwent. We are both angry when we compare the ease of the third treatment course to the difficulties, he had to go through with the first two treatment courses. [redacted] was also given a lot more information about the treatment, and was given some different options to decide upon, with the third treatment. At this time, [redacted] was under the care of Dr Makris in Sheffield. This was different to his previous experiences. [redacted] believes that Lincoln just selected the cheapest treatment course for its patients, rather than giving them any options whilst I had only witnessed being held a part of the decision process, feeling like we, all had a say.

General impact of [redacted]s Hepatitis C

23. [redacted] has always felt reluctant to tell people about having Hepatitis C. I recall him telling me about his diagnosis around six months after we first met. We were friends at the time and I had lots of questions in relation to Hepatitis C because I wanted to understand more about it. I was very nervous when we first started dating because I did not fully understand the extent of his condition. For example, I worried he would suffer a bleed in his mouth and there was a risk he would transmit the virus or if we were going to move to the next stage and have sexual intercourse the best protection to use etc. We were put under a lot of pressure in the early stages of our relationship which for some people would have broken them apart but I believe it made us stronger.

24. At times I have felt isolated and alone with nobody to turn to for support or information as it has not been easy to find for myself. When I was dealing with [redacted] mood swings, particularly when he was on the second treatment for Hepatitis C, I found it difficult to find anybody to talk to who would understand what we were going through, as I did not want him to get into trouble with his own

parents and in turn for my family to have a different opinion of him. It is different now because I have built up a network of friends within the Haemophilia community who I am able to speak with and I know that they will understand. I also think the Inquiry has helped by encouraging me to open up and I have had conversations I would not have had previously with people outside of our network of friends or family. I have friends and colleagues who did not realise that H was infected by contaminated blood products, but as a result of our involvement with the Inquiry, they are now aware, which in turn is educating to those around us.

25. I was H s carer when he was living with the Hepatitis C virus and there is a lot of emotional stress, which comes with that. You always have to remember when medications are required, how much, where to be administered etc. Managing H s care often meant that I would not be able to attend normal events, like Christmas parties at work or go out with friends as I would worry at times for his safety and if he was in a low mood, I did not want to leave him alone.

26. It also makes it difficult to maintain friendships, as we needed people to accept both of us, rather than just being a friend to one of us. Some people understand and make no judgement and others do not. Thankfully my best friend is great and has been very supportive to us as a family.

27. I feel there is a certain amount of judgement that comes with being a partner of somebody infected with Hepatitis C. People just assume you are fine, without realising the stress you are under and the effects it can have as you always need to have a brave face and stand up to it all but it is really hard to be a carer for a loved one.

28. H s diagnosis of Hepatitis C has also impacted things such as holidays. In December 2005, we were on holiday in Prague whilst H was still undergoing treatment for Hepatitis C. After injecting the treatment into his stomach, a lot of pus started discharging from the injection site. We were really concerned by this and decided to cut our holiday short and return home, so that

H could attend hospital. The doctors determined that he had an infection at the site. He had to stay for a number of days in hospital to be treated. Again, further stress to our relationship and health.

29. There was also the emotional stress and worry when you hear of other people dying from viruses contracted through contaminated blood products like Hepatitis C. In the haemophilia community you get to know people and families. This is something that was heard of sharing your Hep c or HIV status but I was not ready to let H go. This is not something you would necessarily consider when you choose a life partner, but it is certainly something that affects you. When H has not been well, he really plummets. He has a really poor immune system and seems to catch anything and everything and it last a long time. It has often made me worry and the worst thing is not being able to do anything to fix it. When you love someone, you just want to take it away and the hardest thing is knowing that you can't.

Impact on our marriage and family

30. In 2010 the Nurses at the Haemophilia Clinic in Sheffield told H and I that Hepatitis C could be sexually transmitted and this therefore impacted our plans to start a family. I would say that we had GRO-B a bit later than I would have wanted to due to having some talk therapy about our options and about the risk of having a child who could have Hep C or in fact me also contracting Hep C from unprotected sex.

31. From 2010 I had to have regular blood tests every six months alongside H regular clinic reviews to ensure that I had not contracted Hepatitis C from H whilst trying for a baby. When we were trying to conceive this increased to every three months and I also had to be tested when we conceived GRO-B to be sure the virus had not been transmitted to me or to her. I would have a blood test and then wait a week until they would call me to tell me the result. I would

say it was the waiting and anticipation of the result of the blood tests that affected me most. I was always worried and expected the worst on every call.

32. The fear of being infected with Hepatitis C when I conceived was huge. I knew that if the virus had transmitted when I conceived that I would not be able to go through with the pregnancy. I would not want to bring up a child knowing he or she would be infected and have to go through the treatment H had to endure. The child may have had the same issues and side effects with their treatment and they would have to deal with the stigma too that H had lived with for most of his life. It was heart-breaking to think like that but I also needed to be realistic.

33. I was very emotional whilst I was pregnant. It felt surreal for me going to hospital to be monitored during my pregnancy, as I was only used to going to hospital for H treatment. We had to have another Hepatitis C test one year after GRO-B was born. This again was nerve wracking, but thankfully it was negative. I have always tried to protect GRO-B from seeing H at his worst.

Financial impact

34. H s diagnosis with Hepatitis C has meant a lot of trips to hospital. This has a financial impact because it means additional expenditure on petrol, parking tickets and time taken off from work to accompany him.

35. The diagnosis also had an impact on things such as increasing the costs of travel insurance for H and becoming a barrier to him getting life insurance. Whilst H managed to get travel insurance with the help of The Haemophilia Society, he still cannot get life insurance today. This has prevented him from getting a joint mortgage and we had to rent for 13 years before I was able to get a sole mortgage.

Section 6: Treatment/Care/Support

36. I understand that H was not offered any counselling or other support as a result of contracting Hepatitis C during his first two treatment courses to clear the virus. When H started the third treatment course in 2016, he was offered a counsellor who was available on the telephone to provide support and advice when needed. We believe it would have been useful if counselling and support was offered when H underwent his first two treatment courses, particularly in light of the issues he experienced with his mood. There was just a complete lack of support during the first and second treatments compared with the third. However, I have never been offered any counselling or support in dealing with H s diagnosis as a main carer his wife.

37. H has also experienced some difficulties when he has visited the GP or dentist, as a result of the stigma surrounding both his Haemophilia and Hepatitis C. When attending appointments at his regular dentist in GRO-B, for example, H has mentioned that his dentist has been dubious to touch him. H is not sure whether the dentist does not really understand Haemophilia and might be worried that H might suffer from a bleed. However, it might have also been out of fear of Hepatitis C and the risk of transmitting the virus.

Section 7: Financial Assistance

38. H discusses the financial assistance received in more detail in his witness statement to the Inquiry. However, I am aware that he received £20,000 one off lump sum payment from the Skipton Fund in around 2002 and also received a larger fridge to store his treatment in. I am also aware that H encountered some difficulties with the Skipton Fund and felt that they made him "jump through a lot of hoops" to receive the fridge when he applied for it before we moved in together.

39. H now receives quarterly payments from the England Infected Blood Support Scheme ("EIBSS"). I am aware that H found the process for applying for support from EIBSS to be a lot more straightforward than it was with the Skipton Fund.

40. H has also encountered difficulties obtaining Personal Independence Payment ("PIP"). Initially, after completing the forms, he was told that he was ineligible. Thankfully, with the assistance of The Haemophilia Social Worker in Sheffield, H successfully appealed the decision and won.

Section 8: Additional information and conclusion

The Haemophilia Society

41. I have been involved with The Haemophilia Society since I met H in 2003 and I attend all of the Annual General Meetings with H and his family. I also took up the role as chairperson within the local GRO-B Haemophilia group in 2014 before this sub-group was closed due to a lack of members.

42. We are still active with the GRO-B Haemophilia group and we both do a lot of volunteering to help raise awareness and take part in fund raising events to raise vital funds for the people living with Haemophilia and Von Willebrand's.

43. We attend as a family all of the events we can including the WFH in Glasgow.

Conclusion

44. I believe so many people could be blamed for the contaminated blood scandal. The aftermath of the scandal, the way it has affected people that contracted a virus from the blood products, angers me the most. I do not understand why H s first and second treatment to clear the Hepatitis C was so bad compared to his third treatment. I would like to understand why there was no counselling or psychological support offered during treatment at these times as I do not believe that H was the only person suffering this way.

45. So many people have died and are dying as a result of the contaminated blood scandal and no amount of money can make this right. I would like the Inquiry to

provide a recommendation on how situations like this will be avoided in the future to ensure that loved ones are not lost to this terrible disaster.

Statement of Truth

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

Signed: GRO-B

GRO-B

Dated: 17.09.21