ANONYMOUS

Witness Name: GRO-B
Statement No: WITN3873001
Exhibits: Nil
Dated: 29 January 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 31st October 2019.

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

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1957. My address is GRO-B. I am retired and live with my husband.

2. I intend to speak about my husband GRO-B: H (GRO-B), who has already provided a written statement to the Inquiry. He was infected with Hepatitis C virus ("HCV") as a result of being given a blood transfusion after an operation in 1988.

3. In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him and our lives together. My statement is to be read in conjunction with my husband's statement.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

5. My husband has been granted anonymity by the chair of the Inquiry, so I would also like to remain anonymous.

Section 2. How Affected

6. In 1986 my husband was diagnosed with ulcerated colitis and by 1988 the whole lining of his colon had gone. He was living on steroids.

7. He was referred to a surgeon involved in trials of a new procedure called a Parkes pouch, which eliminates the requirement for a permanent stoma and replaces this with an internal pouch.

8. The procedure involved 3 operations, during which he was transfused with contaminated blood.

9. I met my husband after the operations and after he found out about his subsequent infection with HCV. Please refer to my husband's statement (GRO-B) for further information on the procedure and how he was diagnosed with HCV.

10. H did stay in contact a lady who had the same procedure shortly afterwards. She did not receive contaminated blood and her body seemed to work much better.

Section 3. Other Infections

11. H did not contract any infection other than HCV as a result of being given infected blood.

Section 4. Consent

12. Please refer to my husband's statement (GRO-B) in relation to consent.

Section 5. Impact

13. My husband and I met in 1993 when we were both serving within the GRO-B Police. H was a detective sergeant running the GRO-B Unit and I was the manager of the GRO-B Department. We were both married at the time.

14. In 1994 H told me that he had been infected with HCV. I recall him saying how hard it was to inform his nieces and how he understood if they did not want him to have any contact with their children. His nieces were actually very supportive and continue to be.

15. We talked about how the virus was transmitted via blood and how we would have to be careful.

16. H retired as a Police Officer in 1998 and in April 2001 I moved away with my then divorced husband. I continued to live with my ex-husband after the divorce due to finances, but I eventually moved out because I could not put up with his behaviour.

17. I GRO-B and started working for the East Sussex County Council. H and I rekindled our friendship and he moved into my house in January 2010.

18. Once we started to live together, I became fully involved with all of H's routine doctors' appointments and hospital visits.

19. After his divorce was finalised, H and I married in GRO-B 2012. H completely retired from the police force in April 2013 and we moved into our current residence in March 2014.

20. In the first two years of our marriage H was fine and had no outward side effects from liver cirrhosis. He had particular dietary needs because of the initial operation on his colon, but we had no real limitations.

21. I knew that HCV could not be transmitted through saliva or sperm, so the infection had no impact on our intimate relationship.

22. H started treatment to clear the HCV virus in 2014 at the Royal Sussex County Hospital. His consultant advised him against starting the treatment because H still had his health at that point. I did not pick up on this comment at the time, but I have since reflected on it.

23. We were informed that for H to tolerate the Ribavirin and to allow the medication to work properly, he would have to increase his fat intake by 20% a day. This was not helped by the fact that a side effect of the medication is a loss of appetite.

24. The treatment started off quite gently and the hospital appointments were weekly to begin with. I remember having to plan for the delivery of the medication because it was all refrigerated.

25. H administered the injections himself and was good at this.

26. H started to deteriorate quite quickly after starting the treatment. He became lethargic, depressed and tearful. I remember one of the nurses suggested that he kept a journal, but I do not know for what purpose.

27. After a month I recall H saying how he did not want to continue with the journal. As the treatment progressed, he felt awful, was not capable of doing anything, did not feel like eating and he became depressed. He could even watch an advert on television and burst into tears.

28. All of a sudden, the cheerful, happy man I knew was not there anymore. I could do nothing other than be there for him, hold his hand and cuddle him. All I could say is that we would get through it together.

29. It was terrifying and heart breaking to watch H deteriorate. I had no support and I was taking anti-depressants at the time. It was the most awful 11 months ever.

30. Even for someone who never previously had a suicidal thought in their head, H had the occasional thought when he could not see a way forward. He was very tearful and a completely different person to live with, his previous inner strength had appeared to have deserted him.

31. I had to be with H constantly whilst he was on the treatment, so I had no alone time, no me time to process what was really going on.

32. As a couple that enjoy travelling, we still wanted to have some holidays in the calendar to look forward to whilst H was on the course of treatment. We created a 'bucket list' in case everything went pear shaped.

33. It quickly became obvious that the travel plans were a stupid idea because H was too unwell to do anything.

34. In the June of that year we took the train to Paris. H was exhausted after the journey and we could not do the activities planned. I

remember he spent one of the days in bed and kept apologising. I felt gutted that I had booked a trip that we had always wanted to do together, but he was too unwell to explore the city. I felt so guilty over this.

35. The hospital staff were honest with us about the side effects of the treatment, but we felt that by improving our lifestyle and exercise, H could work through the course of treatment. I do not recall being told that H would be affected by the treatment for the rest of his life.

36. By the time H reached the end of the 11-month course of treatment, he resembled a skeleton. He even recognised this himself, particularly when he looked at old photographs.

37. When we found out that the virus was undetectable it was an amazing relief and release, but I did not consider the fact that the drugs to this day would leave such a residual effect. I find myself always looking at him for any signs of changes in his appearance and demeanour, in particular anything new which I haven't seen before.

38. H still has bouts of depression and tearfulness and I find that he becomes a lot more stressed now. He continues to get tired very quickly and I have noticed that after a walk his energy levels drop completely. I consciously have to think is this behaviour down to the treatment or something else. It's the unknown that worries me.

39. We used to deal with different aspects of holiday preparation separately, but during the treatment I started to notice H would develop anxieties over minor things and he would stress over them. Nothing I could do or say would help and we would almost be at loggerheads. I would have to remind myself that I needed to be more tolerant.

40. H did suffer with brain fog during the treatment. It is not so bad now, but he does still have moments of it. It can suddenly come on and there is no time to do anything.

41. I worry when H is not really there with me. Sometimes he gets up and is fine for a couple of hours, but then goes quickly downhill. I do not always see this coming on. Usually he will have a headache and cannot get rid of it, so he will have to take a painkiller and go back to sleep. After a couple of hours resting he is ok. It worries me if this was to happen on a driving holiday as we usually share the driving.

42. I thought that the liver was capable of recovering if the HCV virus was cleared, but for H it seems that it has just stopped deteriorating. The information we are given is so sparse and this adds to our frustrations. We want to know more about the results of his liver function tests, to see if the condition of the liver has improved. We find ourselves looking on the internet to see what each part of the test means.

43. We went away the week before Christmas to Dorset. When we arrived at the car park for Durdle Door, I looked at the pathway and knew the walk would be a non-starter. H would not be able to make it up the hill with his breathlessness. I went up to take a picture and found an alternative track that went around the hill. I phoned him up and said about the other route, but 10 minutes later he phoned to say that he could not get any further. We were both upset and for the rest of the holiday we avoided anything that would involve walkingup a hill. I ended up going for walks on my own, which is not what either of us had intended to happen.

44. We assume that the breathlessness is one of the lasting side effects of the Interferon and other drugs used to clear the HCV.

45. It is depressing to hear H say things like "I might not be here for much longer". We have both written a will of our wishes, but to actually speak about the reality of death is hard for both of us.

46. We currently have work being done on the building, which proves aggravating at times. I would like to move away and have a house with a small garden, but this would mean H would have to start all over

again with medical care. We are limited in where we can move to because we need to be close to a hospital with a speciality in liver care.

47. H counts himself very lucky compared to other victims of the contaminated blood scandal, because he had a career and is still capable of doing things now. He is a very positive person and his attitude has always been that this will not define him.

48. I do worry about the health of my husband. He is able to share his worries with me but I have nowhere to share the worries of us both. We have never as a couple been offered any form of counselling.

49. When my husband provided a witness statement to the Inquiry, the Investigator asked if I had been tested for HCV. I have never been asked by any medical professional to be tested. Occasionally I think I should ask, then then I think I should sit out and wait until someone eventually does.

50. I am more forthcoming than H when it comes to talking about the contaminated blood scandal, but I understand that he has kept everything quiet for so many years. I also have to remember that it is not my information to share.

Section 6. Treatment/Care/Support

51. I am particularly angry and frustrated with the level of aftercare H has received since clearing the HCV virus.

52. When H was receiving the HCV treatment, the specialist nurses were very supportive, we would have half an hour with them to talk about anything and to share how we were both feeling. They would explain the next part of the treatment in detail, including the side effects and what to expect. We no longer have these links and often it feels quite lonely.

53. There should be a dedicated team of professionals providing aftercare. It frustrates me that this is not in place. A centre of excellence needs to be set up to assist all those people who have been infected and affected.

54. In 2013/14 H was treated privately through his employee BUPA scheme. Out of the blue he was told that the policy would no longer cover his screening tests. The consultant, Kerry Thompson asked our GP to fill out a form, so H could continue to see her under the NHS. In March 2018 she informed us that she would be retiring, so we decided to move H's treatment to GRO-D

55. After attending the Inquiry hearings in May 2019, H and I went back to our GP because he was not having the 6 monthly blood tests to monitor his liver levels. This has not been successful because we had to organise this of our own back.

56. We had an appointment with the GRO-D on 5 July 2019. Unfortunately, we were due to fly back from Egypt on the 4 July, but the flight was cancelled. When we eventually saw the consultant, Mr GRO-D he was distant, cold, mechanical and barely maintained any eye contact. He looked at just a few sheets of paper and it was obvious that no attempt had been made to retrieve H's medical notes from GRO-B or GRO-B. He made us feel very uncomfortable and we could not have been in his room for no more than 8 minutes.

57. On the 7 August 2019, H had a gastroscopy. He was rather anxious about the procedure being done at a new hospital and with a new consultant, but it was relatively efficient. Once the procedure was over, I was called in and an auxiliary nurse said there was some good news – that there are some varices, but they were only level 1. Varices develop when your liver starts to disfunction. The last thing we wanted to hear was that H had varices, because up until this point he did not have them. I replied that this was not good news at all, because my husband had cirrhosis of the liver and this could develop into cancer.

58. A month later we still had not received a letter from the consultant, so we phoned up to book an appointment for the 16 September. Mr GRO-D could not have been any more different – he was both warm and friendly. It felt as though it was his twin. He explained that he would write to our GP for a prescription for beta blockers and would also arrange an ultrasound scan. He still did not have any medical notes from West Sussex.

59. We were away in Warwickshire not long after the appointment and H expressed some concern about taking the beta blockers. Even when he starting taking blood pressure tablets there were some problems. H does have breathlessness anyway, so I persuaded him to book an appointment with the GP.

60. On 17 October 2019 H had an ultrasound scan and the consultant provided feedback immediately. He explained that there was no outward signs of liver damage and H came away feeling relieved for a change.

61. On 22 October 2019 the GP read the letter from Mr GRO-D during an appointment. He explained that the he would have to work harder on the beta blockers and at times it may feel as though the heart is in front of you. This comment did not reassure me.

62. On 6 November 2019 H phoned the doctors surgery for an emergency appointment because he was worried about his heart rate. It was varying from 40-152 bpm during the day, when he was told that his resting heart rate should be around 60 bpm. H saw a locum doctor, who said that he was not a fan with monitoring heart rate on a smart watch. He instructed H to purchase a 'proper' heart monitor, record his heart rate twice a day and bring the weekly results into the surgery. He commented that they were not that expensive to buy. The locum doctor did not provide a definite answer on whether H should reduce the beta blocker pills.

63. H started to measure his heart rate with a monitor, and the results correlated with the smart watch.

64. On 22 November 2019 H had a doctor's appointment to talk through the figures recorded and we were reassured that the pills were working as intended.

65. We saw the doctor again on the 7 January 2020 because of H's breathlessness. The beta blockers were also making him cold, upsetting his stomach and it was difficult for him to sleep at night. On the way we received a text to say that the doctor was ill, but we could be seen at another surgery. I wanted H to be seen, but we knew we would have to go over his whole history and this is upsetting and exasperating

66. We decided to wait for another appointment with our own GP. We went home to book an appointment online and the earliest availability was 21 January 2020.

67. The reason H did not want to go and see another doctor is because you have to explain everything all over again. He did not see the point of visiting another doctor who will not read up on the notes and progress the case further. It should be the senior consultant dealing with this. It is frustrating and we are both completely discouraged by the health care system.

68. I can understand why H does not want to waste GP time – they are always behind schedule, but I wanted him to ask about the varices and breathlessness. I am worried. He needs to be seen regularly by an expert professional, who knows his medical history in detail. This is not happening at the moment.

69. It bothers me that something important could be missed along the way because we cannot always go to our local surgery or see the same doctor. There is no continuity in his treatment, which is what we find very worrying.

70. Conversely, an example of this is when we were on holiday in Thailand. Prior to leaving H had a blood test and whilst away we had a call from the surgery to say they wanted to speak to him regarding the results. This was an obvious concern. The next day we received a call from the doctors at 2am and H spoke to a locum who was concerned about his liver functions. It actually transpired that they had not changed, but the doctor was not au fait with his current condition and was reading the results in isolation.

71. At the last appointment the doctor did not want to change the medication, but asked H to come back in a month's time. He did not say what he was expecting.

72. The experiences of the last 18 months have made me realise how difficult it is to speak to someone in the medical profession, because you have to explain everything over and over again. Why isn't there any continuity? The extra stress of this just adds to the feelings of helplessness.

73. I want to grab someone and say that none of this is my husband's fault. He did not ask to be transfused with contaminated blood.

Section 7. Financial Assistance

74. My husband has detailed the financial assistance received in his statement (GRO-B).

Section 8. Other Issues

75. From various hospital and doctors' appointments, we have found that a number of NHS staff do not even know about the contaminated blood scandal.

76. H and I attended the Infected Blood Inquiry hearings in May 2019. I found the day very emotional, but it was lovely to be able to talk with others that have been affected. We thought that the hearings were well organised and the barrister probed questions to the witnesses very well.

77. Despite its good work, the Inquiry has had a negative effect on us as a couple. It feels as if the contaminated blood scandal is constantly with us, and the fact that it has been going on for some time makes it feel as though it is never ending. It did not occur to me initially that the Inquiry would have such a negative effect on our well being. However, I understand that this will take time and it does need to be done properly.

78. After my husband's witness statement interview we were very emotional and it took some time for us to let those memories soak back into where they came from. H, because of his occupation as a police officer, is used to compartmentalising things, but I am not.

79. The Inquiry has brought everything back up again for us. H found the statement process hard and today will be painful. When you left today he became very emotional and simply said, I'm sorry.

80. I cannot work out what I want the Inquiry to achieve, but I do want it to come to an end with answers and learning for the future.

81. I would like to see a team of specialists set up to provide aftercare for those affected by the contaminated blood scandal. Even if this was a centralised team in London, the use of technology would enable patients to access care through video link online. With this in place, we would be able to contact the team with issues and concerns. There is no one at present to answer these questions and sometimes we just want reassurance about something.

82. Someone should recognise that those affected by contaminated blood still need support, because we remain in an unknown territory of what to

expect from the long-term effects of the treatment and HCV damage to the liver.

Statement of Truth

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

Signed GRO-B

Dated 29 January 2020