Witness Name: GRO-B
Statement No.: WITN2827001
Dated: 16 July 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B and my address is known to the Inquiry. My date of birth is GRO-B

2. I am writing this statement about my husband, GRO-B: H. He has also provided a statement to the Inquiry (GRO-B).

Section 2. How Affected

3. H was infected with Hepatitis C (HCV) by a blood transfusion he received during surgery in August 1985. H had testicular cancer at the time and required various surgeries to recover from it. Please refer to H's statement for full details of his surgery and transfusion.

4. I did not know H at the time of his surgery. I met him just over ten years later in late 1996. At the time that I met him, I had the impression that he

was not a well person. I knew that he had had cancer before and assumed that he was generally unwell as a result of that. He told me he was being monitored by the oncology team at the Royal Marsden Hospital and attended appointments there regularly for testing to determine if the cancer had returned. Luckily, it had not thus far, but H remained unwell and we didn't know why.

5. In late 2003, around Christmastime, H collapsed whilst out working and was quickly referred by his GP to the Royal Marsden for investigations. I accompanied him to an appointment there on 30 January 2004, and then to follow-up appointments on 13 and 17 February 2004, at which tests were conducted. No information was given to us at the time about what was being tested or what diagnoses were being considered.

6. On 20 February 2004, I accompanied H to another appointment to receive his test results. We were apprehensive, as we were expecting to hear that H cancer had returned. The oncologist took us into a private room, sat us down and promptly asked us, "Have you heard of Hepatitis C?" We said "no", and then he asked "Do you share needles?" We were shocked and confused at the assumption that we had taken drugs. He then told us that H had tested positive for HCV, and sent us to see a nurse who explained that H would need to be referred to a specialist liver unit at Kings College Hospital.

7. It was completely shattering for us to be asked if we have ever heard of Hepatitis C, what we now know to be a life threatening illness, then if we take drugs, and then to receive the information that H had contracted HCV without any context or explanation. We didn't know anything about it or what to do next. I think that the diagnosis should have been delivered more sympathetically with compassion. There should have been an explanation of what investigations they had conducted, why, and what they discovered, before they said "this is what you have". They should have

prepared us before delivering this bad news. We were in shock, as we were still thinking he might have cancer again.

8. I also believe that H should have been diagnosed with HCV earlier. At an appointment with Professor Dearnaley on the 20 August 2004 at the Royal Marsden, we were provided with a document which listed the tests and results which had been conducted over his past 20 years of cancer monitoring. The document showed that his liver function had been tested many times, and that it had become more abnormal over the years. I believe there was enough evidence earlier than 2004 to show that there was something very wrong with his liver, and that someone should have looked at it and tested him for HCV earlier given his history of having a transfusion.

9. There was no discussion at the time of H's diagnosis about the risk of H infecting others, including myself. A few weeks after that appointment I took it upon myself to ask my GP for an HCV test, which came back negative. I find it strange that none of H's doctors said to me that I might be at risk. We had been having fertility treatment and had a normal intimate relationship, so I am thankful that I was never infected. The thought that H may have infected me was a heavy burden for him to carry until I received my result.

Section 3. Other Infections

10. As far as I am aware H was only infected with HCV.

Section 4. Consent

11. I believe that H should have been told what he was being tested for and asked for consent to be tested at his appointment at the Royal Marsden Hospital in January 2004. We were not told what the tests were for until he

received his diagnosis on 20 February 2004, so he was unable to give informed consent to the testing.

Section 5. Impact

12. Throughout his life H has lurched from one dangerous, life-threatening condition to another. There are times when he has been better than others, but it seemed that he was always fighting an illness and complained of being in constant pain. The initial chemotherapy he had was aggressive and put him through a lot. The end result was good in the sense that he survived, but since then he has always had problems with the long term side effects of the chemotherapy. One of the things that worried him greatly after being diagnosed with HCV was the damage this would do to his liver, especially given his pre-existing vulnerabilities. H is especially susceptible to new illnesses because he has a weakened immune system. He has had his spleen removed and takes prophylactic penicillin because there is a chance that any infection he develops will become serious and turn into sepsis. Because he was already vulnerable, getting HCV on top of that was devastating to him. He is anxious about the increased risk of liver cancer. Having had cancer before and suffered greatly, he now constantly lives with the fear that the next illness he has will be liver cancer.

13. H tells me that he has been somewhat disillusioned with the NHS since 1985, as he felt his oncology doctors had failed him. They did not follow up with him after removing his tumour to ensure the cancer did not spread. As a result of this, the cancer did spread and was much worse for him than it would have been if it had been caught earlier. These trust issues with the NHS only worsened when he found out they were also responsible for infecting him with HCV, which has caused him significant distress. He worried that doctors would fail him again and not monitor or treat his liver damage effectively, and that he would develop liver cancer.

14. H and I met in 1996 in GRO-B his birthplace. He had returned “home” to visit his father who was resident there. The first time I saw him I knew that he was unwell, and over the years it became evident that he was struggling with all sorts of health issues from the chemotherapy and multiple surgeries from the cancer. At the time I met him, we were both at a crossroads in our lives, trying to come to terms with personal loss and bereavement.

15. We came back to the UK in early 1997, set up home together and started to build a life. We rented a flat and I got a job with GRO-B as a Careers Advisor. We saved money, and at the start of 2003 we bought our first house together in GRO-B.

16. Although he was able to work and enjoyed his work, H was always sickly. He often had colds or flu-like symptoms and tired very easily. In 1999, he developed pneumococcal pneumonia and was admitted to Mayday Hospital. It wasn’t until 2004 that Professor Dearnaley told him that he should have been prescribed penicillin to take prophylactically after his splenectomy and that if he had been, he wouldn’t have had this particular strain of pneumonia. This added to his distrust of the NHS.

17. Once he had received his HCV diagnosis, H had some difficulty convincing the hepatology team at Kings College Hospital that he was well enough to tolerate treatment. They were concerned about him because he had problems with his digestion and pancreas. They said the treatment would be hard and they were not sure if he was fit enough to undergo treatment. Eventually they agreed that he was, and he began treatment with interferon and ribavirin in 2004.

18. However, the treatment was stopped 9 weeks after it began because he was not able to tolerate it. He had lost so much weight that he was clinically anorexic, and the side effects were so aggressive that he could not manage it.

19. I remember that the clinic he attended to receive treatment was completely full of people. Every seat was taken and patients were lining the walls in the waiting room. They said this was because there were so many infected people coming forward, and it was the only treatment available. I think the news of people being infected with HCV by blood transfusion had just come out into the public domain, and a lot of people had been referred. It felt as though there was a limit on the number of people they could cope with, and too few opportunities to go on the treatment program.

20. H went away for almost a year to recover from the first course of treatment. He knew it was the only treatment regime available and if he didn't get a second chance the long term consequences for him could be potentially fatal. He wanted to make sure he did everything he could to get another chance, given its limited availability. He spent the year trying to regain his mental and physical strength.

21. In 2006, H persuaded his doctors to let him try another course of treatment, which lasted the full 48 weeks. The side effects of this treatment were horrific for him. He was on diazepam for depression and stemetil, an anti-emetic medication. He was extremely weak, fatigued, and vomited every day. His life was put on hold.

22. The treatment resulted in the virus becoming undetectable. However, it also totally shattered his physical and mental health. The interferon and ribavirin have caused long term health complications for which he continues to be treated to this day.

23. Having HCV has impacted on him receiving monitoring and support for his gastrointestinal issues, which have been ongoing since I met him. He has had numerous colonoscopies, gastroscopies and endoscopies, and when he was diagnosed with HCV this meant he had to go to the end of the list for these. The doctors were also concerned that the endoscopes could be contaminated even after the virus became inactive. This was a huge issue

for the hospital because some healthcare professionals thought that they should not take chances even if the virus is undetectable as there is always a chance the virus could recur, which would be unsafe for other patients and an insurance risk for the hospital.

24. H was discharged in 2007 from Kings College Hospital after completing his treatment. His HCV nurse phoned to provide the results of his week 48 test, and confirmed that as the virus was undetectable he would be discharged from the hospital.

25. H did not receive any monitoring or follow-up from Kings College Hospital after this. He was just cut loose. It wasn't until 2017, after we moved to GRO-B, that one of his gastroenterologists asked if he had had his liver checked recently. We said no, and they said it would be a good idea to have a fibroscan to see if his liver had deteriorated and that was somehow affecting his gut.

26. The fibroscan took place at Southampton General Hospital on the 22 January 2017. It should have been a straightforward procedure but it took a long time and the doctor didn't seem to be familiar with people who had been infected with Hepatitis C from NHS treatment. H was asked again if he smokes, and how much he drinks. During the procedure, the doctor seemed to be scanning different areas of his liver until she was happy with what she found. She told us in the end that he has moderate fibrosis. She said the figures are showing that he is not in the category where he needs to be brought back in quickly, but that he probably would need to come back in a couple of years. However, the clinic letter sent to his GP said he does not require follow-up at all and he was discharged back to the care of his GP.

27. He has not been called back in for a follow-up, and it has now been four years since that appointment. He is not pushing for follow up, although I believe he should have it and should have had it then. He felt he wasn't taken seriously, that the doctor somehow thought his liver damage was

due to drinking alcohol even though she must have known how he contracted HCV.

28. In terms of the effect of HCV on our family and social life, H and I are a team of two and our life is quite small. We don't go out in the evenings. If we go out in the daytime, pre-Covid, it would have been for a quiet lunch on a special occasion. We also have a Jack Russell terrier, whom H akes for walks. We have family abroad - H has a sister living in GRO-B that we would visit on holiday. His anxiety has always held him back from doing more things socially. For the longest time he couldn't leave the house, so I would be responsible for day to day running of the house, shopping etc. H also doesn't feel well most of the time and is in pain. He has physical constraints, and gets tired very easily so we are usually in bed by 9pm and if I didn't wake him most days he could still be asleep at 10am. I would describe him as quite frail, and that limits what we can do and the enjoyment we can have.

29. H will be ill and vulnerable for the rest of his life. But we are "okay" because we have each other. We try to make it work. Our life is restricted and we can't do very much. At times we have felt both hopeless and helpless. We do have a sense that time is running out for us.

30. The only other thing that really saddens me about our married life is that when H and I got together we were in our late 30s and quickly realised we wanted to start a family. It didn't happen for us. Our infertility is unexplained. We went through some treatment but they could never pinpoint why we weren't able to conceive, and in the back of my mind, we didn't know at that time about his HCV, which could have been a factor. So we don't have children; we have each other, and we have a dog. That is our family.

31. I think there is still a serious stigma against HCV both in the medical profession and the general population. At the time of H s fibroscan, I could tell that the doctor assumed he had liver damage because of alcohol.

In a general conversation, if you say he has a problem with his liver or liver disease, people always assume it's due to alcohol or drugs. For the longest time we didn't share that H had HCV with family and friends because we didn't know how they would handle it. When we did, there was a lack of understanding about the contaminated blood issue because it seemed to me that people didn't actually believe that could have happened. They didn't want to believe that there was a cover up. I had one person, whom I would consider a friend, say to me "He's had the treatment, and he's recovered now, so it's okay isn't it." As if that makes it right. Some people get it and some people don't, so the best policy is to say very little or nothing because we can't cope with having that conversation. It's a big conversation to have on the back of casually mentioning that you have HCV. It's really painful so we don't go there.

32. H closest friend, who has known him for over 30 years, couldn't cope with it very well at all. He doesn't "do" illness, so he just blanked the whole thing out. He knew H was very seriously ill but couldn't bring himself to discuss it. It was just too upsetting for him to contemplate what might happen. He is still a dear friend, but we don't talk to him about it; we just understand that he doesn't go there. There are very few people in our world who know and understand, and even those people deal with it in different ways and our relationship with them has changed. But we try not to talk about it at all because it becomes the elephant in the room and tends to overshadow other events.

33. H s illness has had a significant effect on his ability to work. Before his diagnosis he was working as a manager at GRO-B store in central London. He left in 2000 as part of a management reshuffle, and set up his own property management business, which he ran profitably for four years. In June 2003, we decided to transition from him being a sole trader to starting a limited company, and as soon as we did that it seemed his health started to fail, resulting in a collapse in December 2003. During his HCV treatments and for a short time afterward (from 2004 to 2009) he was too

ill to work and claimed disability benefits. Then in 2009 he went back to work part time at GRO-B Airport until 2014. Please see his statement for further details of his employment.

34. In terms of my own career, I would say that I have had to let work take more of a backseat and have become more of a carer for H as the years have progressed. I look after him and our little family. When H and I resettled in GRO-B in 1997, I returned to work in the education sector as a Careers Advisor GRO-B. My role entailed working within the community to deliver careers advice, guidance, and intensive support to vulnerable groups, primarily the "hardest to help" unemployed. I worked with a targeted group of young people aged 16 – 19 not in education, employment or training (NEET). My particular specialism involved working with young offenders. I acted as the lead professional to devise, set up and deliver a discrete project to support young offenders into positive outcomes and overcome barriers to learning. I really enjoyed my work. I was very good at it and felt it was a bit of a calling. The natural progression for someone in my situation would have been to take on more responsibility. My team leaders were keen for me to move through the ranks and be offered a promotion to management, but I never felt I could take it, because H became ill at the point in my career when I could have been promoted. H became very seriously ill in 2004, and ever since then he has been my priority. So I remained in post without taking a promotion until the GRO-B was disbanded and I was made redundant in 2011. I am disappointed that I had to pass on the opportunities offered to me. In a managerial position, I would have had the power to influence policy and allocate resources. I feel I could have made more of a difference to help young people in need move forward with their lives. I also consider myself the breadwinner essentially, because when the business collapsed in May 2004, we had just become a limited company after building up the business for four years, and then suddenly his income stopped. All we had to live on was my wage, and it was at a time when the mortgage interest rate was high, so most of my earnings were spent on our mortgage and

bills. We tried to keep the business going because we didn't know what we were facing. Consequently, we built up significant debt which we still have.

35. After I was made redundant in 2011, I was unemployed for three months and then started to work as a trainer with John Lewis At Home in GRO-B I worked there for about a year, and then we became very disheartened about life in GRO-B and had to sell our house as we were struggling financially with its upkeep and debt. We moved to GRO-B, and I transferred to work at Waitrose in GRO-B on a part time basis. We then moved to GRO-B and I transferred there. I have been with the John Lewis Partnership for 9 years. Every time I have made a job move my hours have been reduced, to the point where I now work just one night shift a week. I can't risk bringing Covid home, and there is a high risk of transmission in a retail environment. I have now chosen to work a night shift when the branch is closed rather than leave.

36. My financial security is based on 8.5 hours at Waitrose and two private pensions paid on a monthly basis. Because I have a part time job and two pensions, H and I do not qualify for benefits. Also, the state pension age rise affected me significantly – instead of retiring at the age of 60 it will be age 66 for me. I'm 63, so for the next three years I have to continue working but balance that with my caring responsibilities at home. I feel I am financially vulnerable.

. Section 6. Treatment/Care/Support

37. H had counselling from Kings College during his second course of HCV treatment. He had 12 weeks of counselling with a psychologist. A lot of the focus of those sessions was about coping ahead of time with what would happen if his treatment didn't work, and how to live with the thought that the HCV may progress onto cancer. She was trying to support him through the treatment and take him out of the dark place he was in. The

psychologist was employed by the hospital as a part of the wider Hepatitis team.

38. There was also a dietician on the team within the liver unit. The team cared for people with hepatitis holistically, providing information, support and referrals on to other specialities where appropriate. At the time H was also being referred to gastroenterologists. I feel the liver care programme tried to cover all the bases, except that of course we still didn't know what the treatment outcomes would be.

Section 7. Financial Assistance

39. Please see H s statement for details of the financial assistance he received.

Section 8. Other Issues

40. I am very hopeful that the Inquiry will get to the truth and that people will be vindicated. I am not sure what justice looks like; for some of us it's too little too late. I don't think saying sorry is enough. What I want from the Inquiry is openness about whether there is something going on within the NHS that needs to be addressed. I would hope the Inquiry will make it possible for medical concerns, errors, and bad practice to be brought out into the open rather than being hidden and for whistleblowers to be protected.

41. I also think there should be recommendations made for compensation and ongoing financial support for those infected and affected, sooner rather than later, as people are dying without redress. The EIBSS scheme provides a safety net, but it is not guaranteed to continue indefinitely. H and I (and I'm sure many affected people) are financially insecure. We have no guaranteed income. EIBSS could fold, because there is no law saying it has to continue. Government policy could change. I don't care if

the compensation provided is on the basis of no fault. It is too late to find out who is exactly at fault, and that's not going to help us. I would like to receive compensation for the fact that our lives were completely destroyed and for it to provide some security in our old age. I would like to be able to buy a home; I don't like that I'm approaching retirement and have to pay rent and I worry about my ability to earn money. We wouldn't survive if we didn't have the money coming in from EIBSS. Our quality of life has been ruined, and although we are rebuilding, we haven't had and will not be able to have the life that I believe we could or should have had.

42. I think there should be a national programme of HCV testing, as there are still people who unknowingly have HCV. There should also be education for clinical professionals to reduce the stigma around HCV, and preventative steps taken to ensure something like this this doesn't happen again.

Statement of Truth

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

Signed **GRO-B**

Dated ...16 July 2021............