Witness Name: GRO-B
Statement No.: WITN4211001
Exhibits: Nil
Dated: December 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 21 July 2020.

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

Section 1: Introduction

1. My name is GRO-B and my address is known to the Inquiry. My date of birth is GRO-B 1967. I intend to talk about my infection with hepatitis C (HCV), which I believe I contracted from a blood transfusion in 1975.

2. I have been the GRO-B at Guy's Hospital since 2006 and have worked in this field for about 25 years.

3. I can confirm that I am not legally represented and that the anonymity provisions have been explained to me; NOT RELEVANT

4. I make this statement with the benefit of an incomplete set of medical records. I have obtained some of my records, but there appears to be no substantive record of the relevant period of care.

Section 2: How infected

5. Though it has proved impossible to determine the exact cause of my infection with HCV, I strongly suspect that it arose from treatment I received following an accident in 1975.

6. I was eight years old and was playing in my front garden. I was climbing a wall outside my house and a large chunk of brick work was loose at the top of the wall. As I reached up to climb further, it gave way and I fell backwards to the ground and the loose bricks followed and landed on my arm as I hit the floor. I required emergency vascular surgery; I know I must have lost a lot of blood as my dad spent the next day cleaning blood up off the drive. I had a compound fracture in my left arm and a snapped radius that protruded from my wrist.

7. I was initially taken to GRO-B in GRO-B Yorkshire, but was then transferred to Scarborough General Hospital. I had the surgery here on 16 September 1975 and was sent home the next day.

8. I have no memory of either being transfused or being told afterwards that I had received a blood transfusion. I haven't asked my parents specifically; my father has passed away and I don't think that my mother would know. She wouldn't have been in the room and would not have needed to give consent anyway. I have decided not to ask her if she has any memory of a transfusion as she does not know about my diagnosis – I am healthy now and she does not need the worry. She is old herself now and she may never need to know.

9. I remember getting some flu-like symptoms not long after the surgery. I was only eight years old and had just had surgery, so this could have easily been attributed to something else that I wasn't aware of.

10. As noted, I have obtained a copy of my medical records, including my GP records, but the only relevant entry is a record of a subsequent follow up appointment which notes that my arm is healing well. Looking through my life history, my consultant has concluded that it must have come from a blood

transfusion and that my vascular surgery is the most likely instance of me needing one.

11. I have no other risk factors for hepatitis transmission; I have no blood disorders or tattoos, nor have I ever taken illicit drugs. I have had no other surgery that would require a blood transfusion or had any medical treatment abroad. I am not promiscuous and I am physically fit and have a healthy diet.

Section 3. Other Infections

12. I do not believe that I have been infected with or exposed to any infection other than HCV.

Section 4. Consent

13. As previously noted, if I did receive a blood transfusion during my surgery in 1975, I was not aware of having received such treatment, but I was only 8 years old and was heavily sedated/anaesthetised. I also do not believe that my parents would have been required to provide consent for such treatment and I am not aware of any warnings being given as to the risk associated with any such transfusion.

Section 5. Diagnosis

14. In October 2013, I went to see a dermatologist because of suspected vitiligo. This is a skin condition which affects the pigmentation of cells and I had patches all over my body that were indicative of the condition. I requested a confirmatory diagnosis and, after conducting some tests, the dermatologist confirmed it was vitiligo.

15. The causes of vitiligo are not well understood, so part of the confirmatory check is to test for auto-immune problems. This includes doing full blood tests and, by sheer chance, the registrar that was carrying these out decided to include an HCV test. She said 'let's do the lot'. It didn't include a test for HIV, but I have since had one that returned a negative result.

16. I had a follow up appointment soon after. As my fiancée was with me, the registrar asked if she could speak to me alone. She informed me that the HCV test had come back positive and then referred me to Dr. GRO-D, a gastrointestinal consultant and well-known liver specialist. He is a very blunt man; there was no gently breaking the news. He looked at the bloods and told me 'you are likely cirrhotic'. This was a real shock to me – I saw it as a death sentence, completely irreversible. It was more shocking to hear about my cirrhosis than the HCV itself. I was stunned when told I had HCV – a million things churn over in your mind. How? When? Have I put anyone at risk? But the cirrhosis was something else.

17. I had a fibroscan, which came back very bad. Luckily, they no longer do biopsies – it wouldn't have been safe for me to have a biopsy anyway, because I have low platelets. The scan confirmed that I have extensive liver damage. I remember asking how long I had left. The reply was ten to fifteen years. That was seven years ago.

18. I had absolutely no idea I was suffering from such a serious health condition. I was fit and healthy and I take good care of myself. To then find out that I had such little time left, it was so shocking. I had not experienced any symptoms whatsoever. I knew the timescale for cirrhotic liver disease patients and the likelihood of getting a transplant. You basically have to go into liver failure before you get onto the transplant list. The data show that, at some point, my liver will decompensate and I will have about six months after this.

Section 6. Treatment/Care/Support

19. The only treatment available to me was Interferon, which isn't safe for me to take because of my low platelet count. If I were to have this drug, it would need to be a 12-month course, with frequent platelet transfusions throughout. Dr GRO-D recommended that I did not undergo this treatment. He advised me that antivirals that directly target the virus were likely to become available within a number of years.

20. I faced an extremely difficult decision. The options available to me were not good. I could wait for the new antivirals, knowing that, in the meantime, more damage was being done to my liver. Or, I could begin a course of Interferon, in the knowledge that it would completely knock me out and only has a circa 60% success rate. I was aware of the potential side effects of this treatment and how they would be compounded by my low platelet count difficulties.

21. During this time, I was having three-monthly check -ups, which included running blood and liver function tests, as well as six-monthly ultrasound scans.

22. Then, in 2015, the European Medicines Agency issued a license for a new antiviral drug called Harvoni. Despite this authorisation, it was not available on the NHS. I now faced a different decision. Do I wait for it to become available on the NHS, or do I self-fund?

23. I knew that eventually it would be approved by NICE and made available on the National Health Service – it was just a question of when. But for me, in my condition every day that passed was vital.

24. Even though I ran the risk of forking out huge sums of money only for it to then become available on the NHS soon after, I decided to fund the treatment myself. By June 2015, I had organised to borrow £60,000. I couldn't bear the pain of not knowing how long I would have to wait. It felt like I was playing Russian roulette with my life.

25. Ultimately, however, I was extremely lucky. About a month after I made the decision to self-fund, Dr GRO-D told me that Harvoni was soon going to be made available on the NHS. Had this happened a few months later, I would be £60,000 in debt for nothing. I was, of course, very annoyed that there was any delay at all in making the drug available to everyone. But I work in the NHS and I know how it all works.

26. There is so much politics involved in it all. Trusts compete to become 'Liver Centres' and fight for special status so that they can provide certain treatments. Kings wanted to be the only centre with the authority to provide this particular

treatment. Exclusivity is power. Consequently, there was a delay before Guy's, where I was being treated, was granted status to be a treating centre for this new class of anti-viral drugs whilst the politics played out. It's all about individual consultants trying to enhance their own status. It makes me sick to think that this could have cost me all that money - or even my life.

27. The treatment commenced in November 2015. It was a combination of Harvoni with Ribavirin and lasted three months. It was in pill form.

28. The treatment made me anaemic – my haemoglobin went down to 95, whereas it should usually be around 120. This made me very fatigued and when combined with insomnia caused by the Ribavirin meant functioning at times was very challenging. I still managed to exercise, though it was much harder than before and I could only maintain it for 15 minutes or so. My skin went a sort of grey colour and people often commented that I looked awful. Despite, this I didn't miss a single day of work throughout my treatment. I saw it as more of an inconvenience than anything else. I think my line of work helped me to be pragmatic about the side effects; the cancer patients seen in my service suffer far worse side effects on chemotherapy than anything I was having to deal with.

29. That is not to say that the treatment had little impact on me – the worst consequences were those that effected my mental health. The Ribavirin made me very depressed and it became quite difficult to manage the stresses of my job. Things that didn't used to bother me at all became very stressful and the little everyday pressures often became too much. I remember sitting in a meeting and feeling an overwhelming urge to just burst into tears.

30. These feelings did eventually fade, but for a period of time I definitely wasn't firing on all cylinders. I made my deputies aware that I was on a treatment with significant side effects, without disclosing the exact nature of my illness and medication. I am fairly self-aware and many years in my line of work had made me very conscious of when I am not on top form. I am responsible for thousands of cancer-related tests each year, so it's really important that I recognise the consequences of not being at my best and knowing when to take a step back.

31. After these three months of treatment, I had to wait 12 weeks to assess response, and tests came back negative. A secondary confirmatory negative test is required a number of weeks later to formally document a serum viral response (SVR); this was also negative so I was clear of HCV, the treatment had worked.

32. I am still being regularly monitored; I have six-monthly blood tests and ultrasound scans (USS). The blood tests monitor my liver function for signs of deterioration/decompensation and the USS is hepatocellular carcinoma surveillance, which I am at vastly increased risk of developing due to the HCV-induced liver disease. The theory of 6 months surveillance is based on the average doubling-time of a malignant lesion appearing in the liver, the theory being that if a lesion developed the day after my last USS, the rate of growth of the lesion would make it still operable by the time of my next scan. These check-ups will be necessary for the rest of my life.

33. Regarding confidentiality and privacy, as I work at the same hospital that I am being treated at, I did contemplate going to a different hospital for treatment. Ultimately, I decided this wasn't necessary. It's a big hospital, I did not know any of the doctors and nurses treating me and I know how good the liver care is there.

34. I have made sure to inform both of the dentists that have treated me since my diagnosis. They didn't bat an eyelid. I had a root canal at some point and all they were worried about was me bleeding a lot. I was given tranexamic acid before this treatment to help guard against excessive bleeding.

Section 7. Impact

35. My diagnosis with HCV, as well as the subsequent treatment I underwent, has had a number of considerable impacts on my life. It is most acutely felt in relation to my family life and my relationship with my fiancée.

36. Literally a few weeks before my diagnosis, we had decided to start a family together. However, my diagnosis eventually led to the conscious decision

against having children. I know that the risk of transmission to my partner and any children we may conceive is very small, but it is not non-existent. I just couldn't live with myself if it did happen. I was also just in the process of dealing with my diagnosis and I couldn't bear the thought of having kids that I wouldn't see grow up.

37. This has also had a huge impact on my fiancée. She has had to give up the idea of having a family of her own and we have both had to come to terms with this. Additionally, I'm sure that she must worry about what will happen when I'm gone; I'm the major earner of the household and her family all live in Australia. It certainly plays on my mind and I know it does on hers. For a long time, we each had a very different attitude towards it all. I wanted to know everything and didn't want my doctors to soften the blows. She, however, buried it and perhaps didn't really face the fact that it was terminal. She seemed to think that once the HCV was cured, that was it and it was all behind us. The reality and consequences it seemed were extremely difficult for her to absorb.

38. Neither of us have received any treatment for depression or been offered any counselling, neither at the point of diagnosis or during the treatment process. I believe this is a major flaw with the system. People do need to talk – it helps. A few years ago, when I was really struggling to manage my life with the terminal consequences of HCV, I looked into paying for some help myself, but it would have been eye-wateringly expensive. I managed to compartmentalise and deal with it myself. I have found my level with living with it – it pisses me off now and then, but I am able to handle it.

39. It is hugely upsetting to know that I am unlikely to see a long and happy retirement. It has an impact on every single one of our decisions. Of course, everyone knows they are going to die one day. But being confronted with your own mortality at my age is something very different. It's quite a blow, at 46 years old, to have to start thinking about how my fiancée will cope when I'm gone. I've been putting money into a pension that I know I'll never see. We have started trying to live for now. It's a constant balance between enjoying

life whilst I still can and putting aside resources for my fiancée to have when I'm no longer here.

40. I'd say that it has had a minimal impact on my social life beyond my family. I still like to meet up with friends, though I haven't touched alcohol since my diagnosis. I did enjoy the occasional glass previously, but it's not something I greatly miss.

41. I had lots of lifelong ambitions that my infection has put an end to. I wanted to travel when I retired, go to Australia for a few years and go diving. My fiancée and I are keen divers, but I was told that I shouldn't continue with this hobby. I wanted to pursue it, however, so now I go to a specialist who assesses my fitness before each diving trip. We're now thinking of taking a four to six-month sabbatical to go travelling, but obviously it is difficult to get this much time off work.

42. Not only will it be hard to get the time off, but holiday and travel insurance has become infinitely more expensive. I worried that I wouldn't be able to get insured at all, but I can, even though I pay ten times more than my fiancée. I was fortunate enough to have an existing life insurance policy when I was diagnosed; I wouldn't be able to get one now. If I die with any balance outstanding on our mortgage, this will be paid off.

43. Other than this, and a number of additional costs, there hasn't been any considerable impact on our finances. I don't think that it has held me back in terms of work – not consciously, at least. I have been offered a few national roles but I have turned them down because I am just tired of the job. This may be because my diagnosis has changed my view of the world. Maybe things would have been different had I not been infected, but I can't say for sure. I have struggled to cope with the idea that I will likely be working until I die. It has been very hard to square this off.

44. I have not informed my employer, but I have discussed it with my line-manager. I don't think that telling my employer would have any sort of detrimental impact on my career, but I haven't told a lot of people because I

do fear the associated stigma. I don't want to be defined by it. I don't want people to think they have to put up with X & Y because of my illness. My way of dealing with it is to put it in storage and get on with my life.

45. As previously mentioned, I have experienced very few symptoms that are commonly associated with HCV and cirrhosis. I am on permanent treatment with Beta-blockers as prophylaxis to help prevent a potentially fatal bleed due to oesophageal varices (a recognised consequence of liver disease); side-effects of this treatment are a general tiredness and often feeling cold, as the Beta-blockers lower your heart rate and blood pressure, but these side-effects are liveable with.

Section 8. Financial Assistance

46. Around March 2014, before my treatment had started, Dr. GRO-D told me about the Skipton Fund. He said I'd be eligible for Stage One and Two payments. I sent off the application which I am aware was dated 31/07/2014 but it was returned by the Skipton Fund, who told me that some information was missing from the sections that were completed by my consultant. I went to see Dr. GRO-D, he filled them in and I sent them off again.

47. I later received a rejection letter which I am aware was dated 20/02/2015. It stated that, having looked at the evidence I had provided, they had concluded that it was possible that I had been given a blood transfusion, but not probable. I specifically remember this was the wording that was used. I didn't bother appealing the decision – I had gone to every effort to locate my records from Scarborough Hospital and no other evidence was available. I sent a copy of my replies from Scarborough dated, I have been told, 15&18/11/2013 confirming that my records had been destroyed. I spoke to the Hepatitis C Trust to see if they could offer any advice, but there was no additional help they could provide.

48. I wasn't at all surprised to be honest. In fact, I was expecting to get rejected as I was expecting this to have been set up to make it as hard as possible to actually access any compensation. The real surprise came when I discovered

that my medical records had been destroyed. Having worked in the NHS for such a long time, it is just not something that should ever be done, especially without the patient's informed consent. Obviously, things have changed considerably over the last few decades, but it still shocks me that they were just destroyed.

49. I think it is truly horrifying. I understand that they can't be kept forever, but there surely has to be some reasonable effort made to allow people to access their own medical records. I was planning to use the money, if it was awarded, to fund the treatment that was not yet available through the NHS. It would have meant a year's less deterioration to my liver, potentially crucial for me at the time – this really pissed me off.

50. There was a confirmation of destruction, which noted that they were destroyed 25 years after the period of care. I think it is laughable that the assistance schemes ask people to provide documentary evidence of their infection when they must know full well that most people were infected in the 1970s and 80s and almost always outside of the records retention period.

Section 9. Other Issues

51. The outcome of this Inquiry will hopefully be to determine just how negligent the NHS truly were. I am one of the lucky ones I suppose; fit, well, asymptomatic, still able to work and live something resembling an ordinary life. But that doesn't mean it hasn't had a monumental impact on myself and those closest to me.

52. It's pretty disgusting that the National Health Service caused people to be infected with this virus, then destroyed any record of doing so and denied compensation on that basis. I can appreciate that not a lot was known about the virus, but I think there was a lot of blind-eye turning to the risks.

53. I know how things work in the NHS and how torturous a lot of the processes involved can be. We don't have an endless pot of money and so, unfortunately, you can't give an endless stream of patients an endless number

of treatments. Knowing the reality of the health and pharmaceuticals world means I am able to understand the restraints on treatment. Perhaps this has helped me to eventually come to terms with my infection and the impact it has had although it has certainly not been an easy journey.

54. I was incredibly lucky that my infection was picked up. I could have been dead by now had it not been. Essentially, it is pure chance that I am even still alive today. I know that there are people who aren't this lucky. There are still people alive out there today who don't know they have this virus, as well as many who have died without ever knowing what killed them.

55. People that have been infected need to have their voices heard as do those who have been touched by the ravages it can cause. I was very pleased when the representatives of the Inquiry got in touch. I needed an opportunity to tell my story and I am happy to have had this chance to speak out. I don't expect much to come from it personally, but it means a lot to add my voice.

Statement of Truth

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

Signed GRO-B

Dated 7/12/2020