Witness Name: GRO-B
Statement No: WITN7280001
Exhibits: 0
Dated: October 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B and I live at GRO-B GRO-B GRO-B

2. I live with my wife and daughter. My Hepatitis C (HCV) infection has meant that I am unfortunately no longer well enough to work.

3. This witness statement has been prepared without the benefit of access to my full medical records as many appear to have been lost.

Section 2. How infected

4. Between GRO-B 1966, aged 8, I underwent a GRO-B and GRO-B at Shrodells Hospital, Watford, Herts. There were some problems during the surgery which resulted in a "huge bleed" a few days later, after I had been sent home. I was immediately readmitted to hospital and given two blood transfusions each comprising of one pint of whole blood. It was from these I was infected with HCV.

5. My consultant surgeon was GRO-B

6. As far as I am aware, my parents were advised that the initial operation on my tonsils was very simple and offered little or no risk. With the subsequent emergency readmission, they were given no information or advice regarding the risks of being exposed to infection, prior to me receiving the whole blood transfusions.

7. I would like to add that following my surgeries in 1966, the resultant bleeding and two whole blood transfusions, my parents were advised that the cause was probably some form of mild haemophilia. Medical professionals advised my parents that no tests could be conducted at that time to confirm this as *"I didn't have enough of my own blood left to test*".

8. I am not aware of any subsequent tests being carried out in Watford before we moved away to GRO-B in 1970. I find it surprising that no follow up investigation was carried out by the hospital.

9. Various tests for haemophilia and other clotting disorders over the decades that followed proved inconclusive but did tend to show varying and reduced factor VIII levels, GRO-B I am aware that more recent publications have suggested a possible link between HCV and reduced Factor VIII levels but, as is the case with much of the research, I understand that the sample sizes have been too small to be conclusive.

10. With what I now know, I personally consider it likely that the surgery carried out by GRO-B in GRO-B 1966 simply "*went wrong*" and the hospital might have been trying to avoid blame, particularly given the then prevailing view of the *"infallibility of Doctors"* and thus went with "*the haemophilia suggestion*". I confirm that prior to the whole blood transfusions, I had no history of bruising or bleeding despite leading a very active life and participating in many contact sports resulting in all the knocks and bumps expected of an 8-year-old boy.

11. Another very difficult issue resulting from this is that the suggestion of a mild haemophilia implied that my mother must have passed it on to me despite there being no family history of haemophilia. This created worry and a feeling of guilt for her for the rest of her life (she died in GRO-B and doubtless resentment from my father that his only child could have inherited this condition in some way from his wife. Sadly, both had passed away before the truth revealed itself.

Events leading to the testing for and diagnosis of HCV

12. Having been infected with HCV between GRO-B 1966, it was not until over 51 years later in GRO-B 2017 that I finally had an HCV test and was told that I was infected with the virus.

13. I have had various blood, bleeding, liver and immune system issues ever since that 1966 operation and in GRO-B my immune system suddenly decided to stop performing. It is difficult to confirm this was caused by my HCV, but I see no other reason and anecdotal evidence with the Hepatitis C Trust and elsewhere suggest that it was not uncommon for immune system issues to result from HCV. At the time I wasn't looking for a direct or linked cause for any of my various ailments and certainly not considering HVC. I assumed that my various health issues were just something that happened to people. The initial changes of my immune issues in GRO-B showed up in developing allergic reactions before being diagnosed as Arthritis within a couple of years, the severity of which progressively increased. I started various treatments through the Rheumatology Dept of my local hospital in GRO-B to combat this using initially Sulfasalazine, then changing to Methotrexate, then Leflunomide, then Naproxen. All these treatments had to be stopped and changed following blood tests, some at very short notice, due to my Liver Function Tests (LFTs) and Alanine Transaminase Tests (ALTs) showing very adverse results as a result of the undiagnosed HCV. Sometimes ALTs approached GRO-B iu/L (the norm being <35 iu/L). Between treatments I occasionally had to be given steroid injections, some by my GP and some directly into my joints in hospital, just to keep me mobile when my joints ceased to function. My GP was always loath to do this as this of course can cause its own problems. During this time one of

the male Rheumatology nurses would often make little backhanded and unhelpful comments about reducing alcohol intake and fatty livers which made me feel offended by being unfairly labelled and stigmatised within the department. While I am not completely teetotal, I have never been one for over-indulgence and totally abstained for many years in my 20's. On a number of occasions, I have had ultrasound examinations of my liver looking for possible causes, fatty liver, cirrhosis etc. All showed up as completely clear.

14. In or around late GRO-B having spent years struggling with progressive ill health, my GP GRO-B suggested a change of consultant and hospital. I transferred to the more progressive Rheumatology Department of GRO-B GRO-B and I started a new treatment with anti-TNF therapy involving self-administered fortnightly injections of Humira Adalimumab. As part of the preparations for treatment I was tested for Tuberculosis (TB) and had chest x-rays. I understand that it was also common to be tested for Hepatitis B (HBV) and HCV, but unfortunately these latter tests did not occur for reasons unknown to me. I commenced using Humira on GRO-B and it proved a great success in putting the arthritis in abeyance and making me fairly mobile again. It doesn't repair the already damaged joints, but I was able to walk the dog again albeit on fairly flat surfaces. I continued with regular 3-monthly blood testing which still consistently showed elevated Liver Function Test (LFT) results, which by now were accepted by the Hospital Consultant as just how it was to be with me.

15. In 2017 my GP decided that he really wanted to get some resolution as to why my liver always showed these high results and I therefore started a comprehensive series of investigative blood tests during GRO-B 2017. The result of this was a test that showed a positive HCV diagnosis on GRO-B 2017, of which I was advised immediately.

16. The stigma and prejudice associated with HCV immediately showed itself. The results were picked up that morning by another GP in my surgery with whom I had not had much previous interaction and who didn't really know me or my character but who felt it important to pass on the diagnosis to me as promptly

as possible. She phoned at around 8.30 am and greeted me with the words *"you've been a bit of a naughty boy haven't you!"*, her obvious assumption being that I was or had been either a secret intravenous drug user or had been indulging in some risky sexual practices! The real source was of course identified a little while later. However, I don't believe she was deliberately trying to be awful; I think it was her (rather inappropriate) way of dealing with a difficult situation and trying to calm me down. She was trying to make light of things but it was obvious that the mere mention of HCV, even to a medical professional, invoked questions such as "*what have you been doing so as to become infected*?".

17. I don't recall being given any practical information regarding HCV from this GP in that phone call; we did discuss that it would be sensible to repeat the test to double check the result.

18. My own GP then referred me to the Gastro Hepatitis Clinic of the Gastroenterology Department at GRO-B for further investigation and confirmation. I was then put forward to a panel for approval for HCV treatment with Mavrit which I subsequently received.

Section 3. Other Infections

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

20. I was tested for HIV on a couple of occasions at this time, the results of which were negative.

21. I still find it strange that over 50+ years of various investigations into my blood, bleeding tendencies and liver functions no one ever thought to test for Hepatitis.

Section 4. Consent

22. I also had an HIV test in the GRO-B in GRO-B as part of a work medical. This was not a "*would you like to have a test*?", but rather, being the GRO-B it was "*you are having a test*".

23. My HCV test in GRO-B 2017 was carried out as part of a series of tests. I do not recall if the specific diseases being tested for were spelled out to me in advance. Given my wife's historic background in GRO-B I probably didn't ask as I would have assumed GRO-B GRO-B GRO-B My blood had been investigated so many times throughout my life and I had been having regular, typically 3-monthly, blood tests since GRO-B so the idea of my GP wanting to investigate my ill health further with more blood tests was almost "*routine*" to me. My LFTs and ALTs had been showing as high since the first of this series of tests commencing GRO-B peaking at around GRO-B iu/L in GRO-B (Prior to these tests I had returned a result of GRO-B iu/L back in GRO-B during a work medical. This was followed up on my return to the UK but the focus appeared to have been entirely on Factor VIII levels and Hepatitis was not under consideration.) Figures in excess of 100 had become usual or even "normal" for me. In 2017 my LFTs and ALTs continued to be very high GRO-B iu/L) and that was when my GP said that we must get to the bottom of this. They took about *"4 or 5 armfuls of blood"* in two stages and were testing for anything and everything and not specifically for HCV. Therefore, when a test came back as HCV positive it was a real shock and I would say that I was definitely not prepared at all, prior to the testing, for the ramifications of what being infected with HCV actually meant.

24. I am also aware that the guidance for taking Humira meant that I should be tested for various things, as Humira is such a powerful drug. Prior to commencing treatment in GRO-B I was tested for TB, had x-rays and various other tests which I believe commonly included HCV/HBV as Hepatitis and Humira can react badly together in terms of creating cancers. Due to this, the consultants are ultra-careful not to put anyone on Humira if they have Hepatitis. However, in my instance this latter test was not carried out.

25. As soon as I was diagnosed with HCV, the Rheumatology Consultant immediately suspended my Humira treatment/prescription despite the fact that I had been on this for GRO-B years without any issues and I would have thought that if something was going to happen, it would have happened by now. From a personal and lifestyle point of view, being taken off the drug could have made life very difficult if not impossible for me. I recall historically having major mobility episodes and on one occasion being stuck halfway up the stairs for hours due to the severity of my arthritic symptoms prior to the start of my Humira treatment. I once had to call a doctor to my house to give me a steroid injection so that I could move. Fortunately, at the time of the HCV diagnosis I had just received my latest prescription and had a 2 months' supply of the preloaded Humira syringes that by slightly extending the period between injections (not ideal) I was able to keep going until my treatment/prescription was resumed a number of weeks later. This resumed following consultation with the Gastro Hepatitis Consultant, and I was reinstated on Humira.

Section 5. Impact of the Infection

26. I have suffered various health problems over the past 56 years as a result of my HCV infection, some of which fluctuate from month to month or year to year. Identifying specifics remains difficult of course as the HCV symptoms themselves are so varied and unclear. With hindsight the numerous blood clotting issues, liver problems, stomach issues and immune system problems are more than likely all linked together with the HCV.

27. I was naturally a very sporty child, participating in most sports. I of course got kicked and used to have cuts and bruises like any other sport obsessed 8-year-old without issue. However, following infection the effect of minor injuries worsened. Following a playground kick of the shin when GRO-B old the resulting severe swelling and bruising necessitated a visit to hospital. Subsequent X-rays for the expected broken bone showed nothing but did precipitate a new round of blood tests and enquiries. I was told to stop playing contact sports such as rugby and football and the latest diagnosis was slightly

low factor VIII levels - not Haemophilia but “possibly” Von Willebrand’s Disease. At that age it was really hard to be told to stop doing sports when you both loved and excelled at them in equal measures. I had played in various school sports teams for football, rugby, cricket, and was even a GRO-B GRO-B which will have to remain my last sporting legacy! Thankfully, I managed to channel my sporting desires and abilities into noncontact sports such as rowing and golf instead.

28. As a I teenager I was examined for Periostitis following pains in various joints but again nothing was found. This and other injuries such as severe bruising due to fairly minor knocks, we now know were clearly the HCV at work.

29. I recall my mother taking me to the doctor when I was a teenager due to fears that I had a stomach ulcer following stomach pains and nausea. My mother said that I had a weak stomach. I was tested and had a Barium meal, but nothing came of this. Was this also caused by HCV? It is hard to know as HCV does not have clearly defined symptoms.

30. A broken tooth when I was GRO-B had to be extracted which created major problems. The initial bleeding wouldn’t stop, and after a night bleeding into a bucket I returned to the dentist and was quickly admitted to the local Maxillo-Facial unit at the hospital in GRO-B What should have been the fairly simple procedure of extracting a tooth resulted in a multiple-night hospital stay and minor surgery to stop the bleeding, and I am now under instructions to have any similar treatment in hospital. Fortunately, I haven’t needed to lose any further teeth since then! Thankfully my 1966 surgery also remains my only visit to the operating table

31. Although I only found out about my HCV infection in GRO-B 2017, I have actually been infected for over half a century. Looking back, it is hard to decipher which symptoms have and have not been caused by the HCV.

32. It is difficult to quantify or even list the effect of HCV on my health and my life in the intervening 51 years between infection and diagnosis as I wasn’t looking for anything specific at the time and identified symptoms remain both varied

and vague even today within the published research and via the Hepatitis C Trust. With hindsight, things that happened during my life that I took as "*just me*" or my going through "*one of my phases*" were probably caused by the infection. Minor and major things, such as my bleeding problems, periods of extreme fatigue, some of which affected my academic work and later my employment work, are just some of the difficulties I have endured due to my infection with HCV.

33. I would often describe myself as "*going through phases*" in life and by this, I mean that I would lose interest in doing things for months at a time, followed by periods of total obsession. One example of this would be when I was at university during one term, I scored GRO-B in one set of end-of-term exams, near the top of my year, whereas the following term I only achieved GRO-B in the same subject. It was like my brain just turned off that term and it was certainly not deliberate; in fact, anything but. I had never heard of the term "*brain fog*" until I was diagnosed with HCV, but I feel this accurately describes my experience. When I was at university, the reality of the situation was that I was already GRO-B years into my HCV infection.

34. My blood and bleeding disorders effected my initial career choices on leaving university. My tentative plans to seek a commission in the Army had to shelved at initial assessment stage as it was made clear my medical history just wouldn't be suitable.

35. In my working life one particularly difficult issue caused by my HCV occurred in GRO-B whilst undergoing an employment medical in GRO-B as part of an overall psychometric and physical testing program carried out over a number of days for possible promotion and relocation with my then GRO-B employer. Everything went well until the blood tests, which showed liver function problems with very high ALTs of GRO-B iu/L (ten times the expected normal of less than 35). Consequently, I was refused life insurance in GRO-B and the opportunity of working there. An immediate HIV test was also insisted upon which, while obviously worrying at the time, unsurprisingly proved negative. The clear, unspoken assumption both by the doctors and my

employer was that I must have a secret alcohol problem, again patently untrue. The immediate result was that instead of the promotion with associated major salary increase to GRO-B I was not promoted. In fact, some months later I received a salary reduction from GRO-B to GRO-B and a loss of trust with my employer to the extent that I then left that employment within a year.

36. My next employment involved a large amount of GRO-B into GRO-B GRO-B which started to become problematic within months with various health issues such as aches and joint pains, tiredness and difficulty focusing, beyond anything you might expect with simple GRO-B for meetings with GRO-B clients had to be cancelled at the last minute, which was obviously not good for business or my career. To avoid further problems, I decided after a couple of years that it was simpler to GRO-B and work for myself. To that end I started a small business GRO-B in late GRO-B This of course meant that if I couldn't physically work or my brain just decided to 'turn off' then, while I would only be earning a restricted income until I got fit, at least I wasn't having the stress of letting an employer down. I could liaise with clients, if somewhat inefficiently, from home by phone and fax. This was before the common use of the internet and email and long before home working became a trend.

37. For most of these years I have suffered with immune system issues resulting in allergic reactions to various things and occasional angioedema. Large golf ball size angioedema swellings on the lips and face create their own issues such as the obvious one of choking. Additionally, the effect on my appearance causes self-consciousness and embarrassment and therefore my not wishing to be seen in public until they subside. Other issues such as "*brain fog*" come and go

38. As previously mentioned, my immune system problems accelerated from GRO-B Needless to say, with all of these mobility limitations this dramatically affected my ability to work and carry out my GRO-B You can't visit clients if you can't walk, climb stairs or visit projects easily. I became progressively more unfit as all exercise stopped and I still haven't played golf, which I had been playing since I was aged GRO-B after being advised to avoid contact sport,

since about GRO-B While you can drive around the course in a buggy it's difficult to play if you can't then grip the club!

39. About GRO-B years ago, prior to the HCV diagnosis, I incurred a problem within my throat where a small "pouch" had developed that can occasionally trap quantities of food causing my body to react by creating an involuntary choking reaction to try and eject it. When this occurs, it can take one minute to half an hour to clear and to onlookers can appear very distressing. When going out for a meal I always have to prewarn whoever I am with of the possibility to this occurring which can be very awkward with business lunches and can lead to me avoiding social situations like meals out with friends and cause anxiety around eating. Investigation in hospital revealed the problem but the solution of minor surgery would involve cutting open my throat to repair. Given the potential for excessive bleeding to occur if something were to go slightly wrong when exposing various arteries etc. it was decided not to progress with this operation and to just "try and live with it" and hope it doesn't develop to a more dangerous and uncontrollable level. Because of my bleeding tendency as a result of my HCV I continue to have this issue to this day.

40. More recently the HCV diagnosis itself has caused immense stress and anxiety, firstly from my infection with HCV and secondly resulting from the Covid situation and implications linked to my HCV. This has and is affecting both myself and my wife and daughter causing mental health problems for all of us as a family. I was classed as "*at risk*" for Covid19 and had to be extra careful about isolating and endured very restricted behaviour during the pandemic. I had my 3rd booster (5th vaccination) in October this year. Currently, I would describe myself as being fairly mobile albeit with ongoing pains in damaged joints due to the 20+ years of Arthritis which continues to be treated. The use of the very strong Immunosuppressant drug, Humira/Adalimumab, since GRO-B has allowed my arthritis to be controlled.

41. As a result of reactions from medical professionals throughout my HCV diagnosis and treatment, and out of fear of prejudice, stigmatisation or embarrassment or all three, I have not discussed my diagnosis with anyone

apart from my wife, who I've been with since GRO-B and my daughter. I felt if this was the reaction of knowledgeable people within the NHS how would friends, wider family and the general public react? This whole diagnosis was naturally extremely stressful and worrying for the pair of them and my wife had of course to then go through the same tests herself in case I had infected her. Thankfully I had not. My daughter had to undertake a period of counselling to assist with her anxiety. Knowing the diagnosis and how lucky I am to be alive creates its own problems particularly in respect of my mental health and anxiety creating a desire to avoid conflict, thus making continuing in a small business very difficult. The pressure of actually asking people to pay for my services, the most basic part of business, became incredibly stressful to the point where I often just couldn't do it. Even supposedly simple tasks like making a phone call or answering the phone can make me very anxious and required a lot of mental effort which did not always happen. My business started to quickly deteriorate.

42. Following consultations at the Gastro Hepatitis Clinic of the Gastroenterology Department at GRO-B and following approval by a panel, I received treatment with Mavrit, a relatively new drug, commencing on GRO-B 2017 and lasting 8 weeks, which was completed on GRO-B 2017. I had consultations with the specialist nurse GRO-B of the Consultant, GRO-B GRO-B and on GRO-B 2017 she confirmed that I now had an undetectable viral load. Tests were repeated 3 months later which confirmed this and that I now had achieved a sustained viral response. I was then discharged from the clinic. It was via GRO-B that I was introduced to the EIBSS who accepted my claim on GRO-B 2018.

43. After the onset of the Covid pandemic my wife and daughter understandably became even more worried about my health and extremely protective of me. I remained in semi-isolation for most of 2020 due to my impaired immune system and still only venture out carefully and avoid things like public transport. I have now received my 5th vaccination.

44. I have now had to stop work and closed my office and business in GRO-B which had been on a downward trend for a number of years post diagnosis, due to my inability to continue working. Since this time I have not worked and just lived off savings, which are reducing quickly, the EIBSS payments, and my wife's small GRO-B pension. I do not and nor have I ever, made any other claims or received any other form of financial support or benefits. Due to the closure of the business my wife who worked with me for the past 25 years was also left without a job.

45. But for HCV who knows where we might be income wise. I expect I would have worked for a GRO-B likely in GRO-B My role in GRO-B was GRO-B GRO-B and after I moved to the GRO-B my title was GRO-B With my hard-working ethic and drive I expect that finances would not be anything like they are for us today.

Section 6. Treatment/care/support

46. I felt the stigma and possible prejudice I'd previously experienced with "*suggestions*" of alcohol problems as a result of my high LFT results had now moved up a level with the virus and I felt this continued later after I advised my Rheumatology Consultant in GRO-B of the diagnosis who immediately stopped my treatment claiming it was "*too risky*" to combine Humira with HCV. This seemed rather strange to me as I'd clearly been taking the medication for the previous GRO-B years with HCV and lived. The decision was reversed some weeks later after discussions with the Gastro Hepatitis Consultant. Subsequent correspondence from the Rheumatology department continues to have HCV headlining it which I find rather unnecessary and could lead to prejudice from people who do not know or understand my situation. After my complaining about this it has been at least qualified by the addition in brackets of *(Contracted during surgery)*.

47. I have not been offered any counselling or psychological support in consequence of my HCV infection.

Section 7. Financial Assistance

48. I found out about EIBSS via GRO-B the Consultant Nurse at the GRO-B where I underwent my Mavrit HCV treatment. EIBSS accepted my claim on GRO-B 2018.

49. I currently receive approximately GRO-B per month which equates to GRO-B per annum. I also receive the Winter Fuel Allowance.

50. I have never applied for or received any grants or other payments.

51. I found the application procedure straightforward and was assisted by GRO-B and my GP GRO-B in this regard.

52. I have not had much interaction with EIBSS. I think they could do more to publicise the fact that grants are available to assist victims. Perhaps providing more clarity and possibly the option of direct personal assistance in terms of exactly what you can and cannot apply for and how to do it. I believe there are only a little over 3,000 people currently receiving support from the EIBSS, a number which I imagine is sadly reducing year by year as people continue to die from the diseases. With such a relatively small number perhaps a dedicated team could offer direct and personal communication, bespoke personal emails being the obvious starting point, which could provide that simple, more direct link for the Beneficiaries with the EIBSS and its services? I am sure many people are both confused and nervous about entitlements, form filling and application processes for additional support so the availability of one-to-one advice, if required, may be greatly appreciated.

Section 8. Other Issues

53. I would like this Inquiry to raise awareness for both the Government and the NHS to take responsibility for their actions however historic. While my personal experience of individuals within the NHS at all levels has been positive overall,

my GP GRO-B and the Specialist Nurse GRO-B at the Gastro Hepatitis Clinic springing to mind as outstanding examples, there have also been a few individuals who have not been so supportive and their complacency I sometimes felt stigmatizing and offensive. That degree of professional arrogance that existed in the 1960s and beyond where Doctors and Consultants could not be questioned has hopefully moved on. However, there are still some people in the profession who treat patients as a little more than a number forming part of their daily 9 to 5 and occasionally as if a "problem on the production line to be dealt with". It is vital that they always remember patients are people and that to the patient everything is new and personal. They must always consider and examine the consequences of what they say and do. Sometimes people seem to just want to pass the buck and are not prepared to sit down, take ownership and analyse what went wrong and what needs to be done. They are too focused on "*moving things off their desks*".

54. I also feel a more universal and proactive process of testing, instigated by GPs' recommendations direct to their patients, would be beneficial to help identify those people who remain unidentified, often because they have never thought themselves at risk and therefore have never put themselves forward for testing.

55. I also think it is vital that adequate and sufficient compensation is granted to those infected and affected by this tragedy. To quantify this is impractical on a case-by-case basis as everyone is so different and obviously Government departments have a responsibility to be careful with spending tax payers' money. Spending too much time and money delaying, analysing ("paralysis by analysis?") and reviewing is also counterproductive and decisions need to be simplified and above all sped up as with the recent interim payments. Those of us infected are dying all the time and earlier than we should have. The impact on my life and the life of my family, and of other people's lives similarly affected, caused by being infected is immeasurable and no monetary amount can ever compensate for this however it can help us be more comfortable and be able to still support our families when we are no longer able to do so ourselves. The compensation needs to be at a level which allows one to live a comfortable life.

Anonymity

56. I wish to apply for anonymity.

Statement of Truth

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

GRO-B

Signe ....

Dated............14/11/22..............................