Witness Name: GRO-B
Statement No: WITN5522001
Exhibits: 0
Dated: February 2021

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 1967 and I live at GRO-B GRO-B. I am married (for GRO-B years) to GRO-B and have one daughter GRO-B who was born in 2004 and is a carrier of Haemophilia B.

2. I was infected with the Hepatitis C Virus (HCV) through contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my medical records.

Section 2. How infected

4. I have severe Haemophilia B with less than 1% clotting factor.

5. I was under the care of Professor Hardisty at Great Ormond Street Hospital (GOSH) from when I was diagnosed with haemophilia at 9 or 10 months until 1980 when, at aged 13, I transferred to the Haemophilia Centre at St Thomas Hospital, Westminster under the care of Dr Geoff Savidge (Geoff), the Centre Director.

6. I was treated (on demand) at GOSH with full plasma (FFP – full frozen plasma) until 1973 when I went onto home treatment of Factor IX (FIX) concentrate. I was given a variety of untreated FIX products before the heat-treated versions started, the last heat-treated product being Alphanine, and I then transferred to recombinant Benefix in 2018/19. (I also used Alprolix and Refixia sustained release FIX, but it was not effective once a week, so I returned to Benefix and use it to the current day.)

7. My parents were not pre-warned of any risk of infection before I was treated with blood products. I first became aware of the risk of infection in 1981 at a routine appointment with Geoff. I remember sitting in Geoff's very small consulting room with him sat on his wheelie chair in front of me when he began a discussion with me about my HIV status. He went on to tell me that I was 'HIV negative'. I did not know what HIV negative meant, and I did not know I had been tested for the infection. I remember asking him if being HIV negative was a good thing or a bad thing. He said that neither outcome was 'bad' but that if there was a choice it was better for me to be negative than positive. Over time (and with all the very frightening and upsetting media coverage), I became aware that a negative result was the perfect result, and a positive result meant that you had a death sentence. I was then tested for HIV twice a year. I would

begin to close down inside myself with terror weeks before my six-monthly appointments. I would physically shake and have nonstop nausea during the weeks before the test and this would continue until the test was done and the results confirmed weeks later, and that feeling of terror and dread went on for years and years (into the early 1990s) until HIV testing stopped.

8. I was given up to five doses (injection vials) of Factor VIII (FVIII) concentrate in 1983 as an inpatient at St Thomas Hospital for a knee operation and I believe that treatment to be the likely source of my HCV infection given I believe FIX infection was far more rare. Geoff was paged to come to my ward at midnight after a serious post-operative bleeding episode. I remember him standing over my bed, and saying to the nurses I needed an urgent blood infusion or they might lose me. They also took a blood sample to test, and it was from this that Geoff told my mum and I (who had been contacted during the night and had come to the hospital urgently) that my FVIII levels were low, hence the need for FVIII concentrate (in addition to the whole blood transfusion I had had the night before). Geoff' diagnosed me as having mild Haemophilia A in addition to having severe Haemophilia B, but with no percentage level. I always liked Geoff for his directness. I thought he was fantastic and my opinion of him has not changed. (Incidentally, I was later given FVIII concentrate instead of FIX concentrate, in error, ahead of a holiday in the Gambia in approx. 1990 and I unknowingly used it for several weeks.)

9. I am not clear exactly when I was told that I was infected with what was referred to then as 'Non-A, Non-B Hepatitis'. It came across when told that it didn't then seem to be much of an issue compared to the dangers of an HIV/AIDS infection. I was still having my HIV status checked every six months as it was unclear how long after someone was infected that the virus would be detectable. At one of these post testing consultations Geoff Savidge told me at a that I was negative for HIV 'but you have a little bit of Non-A, Non-B. Don't worry. Carry on as

normal'. I was not told that I had been tested for hepatitis before being told of the result.

10. I was not given much information and/or advice about managing the HCV infection. There was no treatment and I was told that I would have to live with it. I believe I was told it was unclear how it was transmitted outside of blood products but to be careful. I had a girlfriend and had to take precautions. It was only years later when I was told that I had a much higher chance of developing liver cancer, and was told about a treatment trial to try to eradicate it, that I understood the gravity of having HCV and that it too could be a death sentence in the long run.

Section 3. Other Infections

11. I was not infected with anything other than HCV.

Section 4. Consent

12. I was tested for infection without my knowledge, consent and without adequate information.

Section 5. Impact of the Infection

13. The psychological/mental effect of having to worry about HIV and the need for ongoing tests for many years every six months to see if it was detected was huge. It felt to me like a death sentence every time I had to then wait three weeks for results. It used to make me physically sick with worry and ended a

relationship when my girlfriend at the time found out I was a Haemophiliac and made the link with potential HIV.

14. After learning that I had HCV, as a self-survival mechanism I had to try to push it to the back of my mind as I had it, and there was no treatment available. I was always very concerned, especially when the LFT's (Liver Function Tests) were tested twice a year, in case something abnormal came up. I was told that a prolonged HCV infection could give rise to liver cancer. Lesions were found on my liver and I was told then that there was a higher risk to me of developing liver cancer. I am, as a result, scanned annually which again continues to be very frightening. There have been some occasions when an upgraded scan has been needed which I always know is because some unusual results have been identified, but thankfully all have been ok.

15. I was on Interferon as a clearing trial for six months from 22nd July 1996. I had immediate side effects of flu symptoms, and headaches lasting about 10 days to two weeks. I couldn't work for most of that first week after treatment (I went in for one day on the Wednesday). I had to self-inject into my stomach area twice weekly which was painful as the whole area was bruised and I had to inject through the bruises and do that for six months. I was very irritable and short tempered, and I was never like that before the treatment. The treatment didn't work and was stopped after six months.

16. I met my wife GRO-B in 1993 during a period of hospitalisation following another knee operation GRO-B in St Thomas that looked after me. As such she supported me during the first interferon trial in 1996 and the intervening four-year period between my first and second attempt at clearing HCV with a combination of Interferon and Ribavirin in November 2000. The first attempt was so difficult and horrific I didn't think I could go through it again. GRO-B a RGN staff nurse by profession) encouraged me to do it and supported

me throughout. I did it for her. She had to talk me into it. I experienced the same side effects initially although slightly less. However, I became noticeably irritable and volatile. I was like a coiled spring, ready to snap at anything. I had an inner rage and was constantly having to wind myself back in. I didn't like noisy places, and all these characteristics/effects continued post treatment and to this day. As I couldn't stand noise or crowds, it impacted my private life greatly, as it stopped me going out a lot and socialising or having people around as it made me very anxious. Once again, I got bruising from the injections into my stomach area but had to continue injecting through the bruises which was very painful.

17. I was counting down the days to what I thought would be the end of six months of treatment, thinking that it would again fail, and I would be relieved of the painful and mental burden of having to continue with it. It was that awful. When I was then found to be clear of the virus after 6 months, I burst into tears and was inconsolable as that meant I would have to continue for another six months, totaling a full 12-month treatment period. I found the treatment so awful I was desperate for the interferon/Ribavirin trial to fail so the trial would stop, but with GRO-B support I continued and completed the full 12 months. I have stayed clear of HCV ever since although the side effects didn't stop, but I would never want to relive that time as even talking about it makes me very upset even to this day.

18. My wife was always worried about contracting HCV through sexual contact despite precautions being taken. We delayed having a family (until 2004) as I had to be at least 18 months clear of the HCV treatment and it affected us having more children/our family size for fear of passing on the infection(s) that might emerge/re-emerge between tests. It impacted our family and where we could go on holiday and affected days/nights out due to the continued mental side effects of the treatment. I wouldn't go to pubs/clubs or large family celebrations due to noise and how busy it would be. Often my wife would attend

events on her own or with our daughter if it was a concert or children's party. In addition GRO-B has had counselling during 2019 and 2020, partly down to the stress of supporting me through the HCV inquiry news and the claiming of the various financial support awards as well as dealing with my mood swings and anxiety.

19. I have a constant feeling/belief that I am not going to survive into old age due to the impact of having HCV over a sustained period of time (cancer being one example) and think about what that means for my family in the future when I am not around. This is constantly a worry in my head. My family have to put up with my mood swings and shut down periods which has been very difficult for them and continues to be to this day, even after years of psychological support.

20. I can't get life insurance renewed and my travel insurance went up once HCV was added to the list of issues as seen as a separate issue, not linked to Haemophilia.

21. In terms of fear and stigma, and especially during the 1980s, I was always far more concerned about my HIV status, terrified that it would change the next time I went in to be tested. Not many people knew I was a haemophiliac and I was always worried that people would look upon me the same way they looked at anyone with HIV/AIDS believing that I was likely to have it. In the 1980s people thought you were dirty or not safe to be around. Someone once asked if I was a haemophiliac and when I said 'yes', they said 'oh so you have AIDS then' as though it was a sure fact that we all have this. Some people wouldn't talk to me even after me telling them that I didn't have it. It was horrible to live with and I shut myself off from a lot of people.

22. I had to always tell clinicians and medical teams that I had HCV even after I had been cleared of it. I once collapsed at GRO-B Station and they asked me if I was HIV negative before they would touch me.

23. My parents always told me to be proud of being a haemophiliac, but they, and I, had to stop telling people as people would assume I and my extended family could be HIV positive or have AIDS. My parents had neighbours that wouldn't speak to them. This upset them greatly. My mum once had to listen to a church sermon with the vicar saying that it was homosexuals and dirty people who were getting HIV and HCV. She was furious at that and told the vicar so after the service resulting in them sending a written apology to my parents. When I first met my wife, she too wouldn't tell people I was a haemophiliac for fear of them assuming I had HIV/AIDS. She didn't tell people including her own parents that I had HCV for fear they wouldn't understand. They eventually were told but only once I was HCV negative and after GRO-B was born. To this day, even though people are now far more informed due to the Inquiry hitting the headlines, she is cautious and reluctant to tell people of my Haemophilia.

24. Studying was hard for me due to always being tired from the Hep C infection and hence I tended to struggle at school. I had to repeat my first year of university three times but couldn't get through it due to my tiredness, so then left to get a job. I tended not to tell employers about my Haemophilia and HCV status as I worried about their reaction.

25. I didn't miss much work over my 30-year career, and when I did it was usually because of an operation. I would only really open up about my Haemophilia to people after I'd known them for about a year and a half. I didn't want to be labelled as GRO-B the Haemophiliac' rather than just GRO-B I would then try to throw the information into the conversation, pretending that I'd mentioned it before and that it was just a really casual thing, so that they hopefully didn't think it meant anything and didn't change who I was. I wouldn't tell people I had HCV so only had support from within the family and I couldn't tell friends as I feared their responses.

26. I have worked from home since 2000, mostly because the HCV treatment made me very tired/fatigued. The treatment caused a lot of long-term issues, some of which meant that I tried to avoid standing in crowded or noisy places – otherwise I would begin to panic and my anxiety would be increased. I couldn't cope with cramped trains or hot and stuffy underground stations and as a result the company I worked for allowed me to work from home for 19 years. I found my anxiety has stopped me doing any corporate events or training courses and also presenting to people as my anxiety would become debilitating. I had to adapt my working and the jobs I could do around my limitations. If not for the HCV/treatment I probably would have been able to continue to do my job without any issues.

27. Due to company policies, I had to have my work location tagged to a certain location other than home, and my closest was always GRO-B It was announced however in 2019 that The GRO-B office was being closed down. I was told I could either move to the GRO-B office (a two-hour drive from my home) or I could take voluntary redundancy. If I didn't choose either I would then be made compulsory redundant. I was extremely upset about it as I had worked for GRO-B from home for such a long time and enjoyed my job, and yet this did not seem to make any difference. The reality is that the tainted blood inquiry and the news coverage opened a Pandora's box on all the pent-up anxiety I had lived with most of my life. I went off sick for three months in late 2017 with anxiety and then again, a year later initially for a kidney stone removal (which would normally mean I would have been back within a matter of days) but stayed off for a month due to anxiety. In my opinion I truly believe that my redundancy in November 2019 was linked to the company looking at my performance and sick record and my poor mental health and the limitations it put on my work over the last 3 years, and took the opportunity to lose me.

28. I suffer with extreme anxiety (synonymous to continuing/multiple PTSD) even to this day, even after three years of clinical psychology support (November 2017 -

December 2020 in last 3 years). The tainted blood scandal hitting the headlines was the trigger for my anxiety, as well as claiming the initial financial support exacerbated in late 2018 by the completion of the form to claim the increased SCM (Special Category Mechanism) Government financial support (EIBSS). Each claim forced me to relive periods of my life that were horrific in many ways and going back to them meant, I fell apart emotionally and mentally Reading the psychological impact criteria section on the EIBSS form, for the first time made me realise that all the things I was experiencing and didn't understand could be linked back to the HCV and its treatment. It was all there in black and white. I recognised all of it in me.

Section 6. Treatment/care/support

29. I have received clinical support (Clinical Psychologist) for over three years some of which was available to me through my GRO-B private health care policy, but the last year (late 2019- Dec 2020) I paid for myself as the private healthcare withdrew their funding as they felt it was an ongoing issue. I would have welcomed counselling during the 1980s and during and after my HCV treatment.

Section 7. Financial Assistance

30. I had my DLA removed (awarded partly for Haemophilia, but also fatigue and other HCV related effects) when the benefit transferred to PIP. However, when the Infected Blood Inquiry hit the headlines the Government asked that all haemophiliac PIP claims be reviewed again separately. I then found out that my PIP would be granted despite no additional information or interviews from me. The decision was based on original information from me that was not deemed

sufficient the first time around. I relied on that money and went without it for six months.

31. I was advised by St Thomas Hospital about the Skipton Fund in 2004 and received the Stage 1 £20,000 payment in late 2004. It was quite straight forward.

32. I found out about American Legal via the Haemophilia Society, not sure exactly when though but started the application process in August 2007. I received £3000 in 2010 having been told that unless 95% of claimants agreed and signed up to it, no one would get anything at all. I didn't want to sign as I wasn't financially hard up at that time but felt I had to for those less fortunate than me. I felt very pressured into signing it. It was a complex three-year process dealt with on my behalf by solicitors in GRO-B

33. I was advised about EIBSS by the Skipton Fund as five funds were coming together into the single EIBSS in 2016. I successfully applied under the new scheme for a basic annual payment of £3,500 and £500 winter fuel allowance, EIBSS told me about the Special Category Mechanism in autumn of 2017 (just prior to my 3 months sick leave). In 2018 I successfully applied for the Special Category Mechanism which means I am currently receiving £28,546 a year (paid monthly) and winter fuel allowance of £540 paid in November each year. I received the sum of £840 towards counselling costs in June 2020.

34. EIBSS required a lot of paperwork as well as evidence from other medical professionals and I found the process of applying challenging as well as very upsetting as it required me to think about things that I had spent a long time trying to forget relating to HCV. I had to relive situations I wanted to forget. I had to self analyse myself to understand how I felt and the impact this had had on me, which given it upset me at the time was going to have a negative impact on me during the application process.

35. It also made me have to delve into feelings that at the time I had deliberately not wanted to think about as a self-survival mechanism and yet this process required me to comment on them and understand truly how I felt. The process actually caused me to require clinical psychologist support on how to deal with some of the memories I was now having to face.

36. Most Trusts and Fund applications were time consuming requiring a lot of record checking and going to others for dates and times. These awards and funds were very welcome but it took far too long for them to be provided. As a person who wanted to be normal and independent and spent a lifetime not wanting my medical issues to gain any advantage, it felt very demeaning to have to fill out the forms which made me feel I was having to almost "beg" for what was really already, in my view, clinical proven ie the blood was tainted, I contracted HCV and was treated and had long term effects from it. It really shouldn't have required the upsetting process that it did, as in my view it should have just been a decision based on the likelihood that my HCV was down to the tainted blood thereby avoiding the mental anguish that the process put me through. It felt to me as though the Government waited until enough people had died to limit the financial burden. Although the EIBSS award is welcome and will make a massive difference going forward, there was only very small financial recompense (only the Stage 1 payment of £20k from the Skipton fund in 2004) for the period from infection to the point they started paying via the EIBSS funds, for the physical impact of growing up with HCV, the mental torment of living with it as well as the anxiety of the HIV/HCV testing, or the impact it had on my family and I on a day-to-day basis.

37. The EIBSS award/fund does not say or guarantee that the award is "for life", it just says "indefinitely". As such, a major worry is that at some point a Government will withdraw it leaving me, for one, financially broken. It would

make a real difference if the Government agreed that these payments were "for life" and this was a legal/regulatory undertaking which could not be overturned, as then people could be assured of its continuation. As an example, my original DLA award said it was "for life" as Haemophilia doesn't get better over time, and yet, when I had to reapply for it as the PIP it was turned down – hence my very real worry that this financial support will get withdrawn when it is no longer news worthy. This concern is in my mind constantly on a day-to-day basis, waiting for the inevitable change that will mean the money is gone.

Section 8. Any Other Issues

38. I went through Gene therapy in 2010 under Professor Tudddenham at the Royal Free Hospital which was alas unsuccessful, so I continued on with FIX prophylaxis treatment twice a week. Whilst unsuccessful for me, I understand that it worked for the rest of the trial group and I have been told that my input has been invaluable as part of that trial such that this treatment will become commercially available later in 2021/22. I am delighted for future generations of Haemophiliacs, with my daughter (a Haemophilia carrier) in mind.

Anonymity, disclosure and redaction

39. I am seeking anonymity and understand this Statement will be published for the purposes of the Infected Blood Inquiry.

Statement of Truth

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

Signed **GRO-B** ......

Dated...... 22/02/2021 ....