Witness Name: GRO-B
Statement No: WITN2556001
Dated: 19th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 13th November 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

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

1. **Introduction**

1. My name is GRO-B . My date of birth and address are known to the Inquiry. I confirm I am employed as a company director. I am also a Trustee of a local charity which is a voluntary role.

2. I confirm that I suffer with mild haemophilia A. This did not affect my life greatly in my younger days and I pretty much led a normal life. I did not have any prophylactic treatment for haemophilia but had occasional issues with bleeding. If I had a severe bump or a cut, I would need treatment to control bleeding.

3. There is a history of hereditary haemophilia in my family and my younger brother and two cousins were also born with mild haemophilia. My grandfather and my great uncle both had mild haemophilia and, to provide some context, my grandfather lived to the age of 80 and my great uncle to the age of 92.

4. I had numerous short stays in hospital up until the age of 18 for more serious bouts of bleeding. For those earlier incidents I was treated with cryoprecipitate, however my records show me having received concentrated factor 8 as early as 1972. I was also treated with whole blood transfusions on a number of occasions where I had lost blood through internal bleeding.

5. I was taught to self-administer factor 8 from the age of 16 and kept factor 8 at home for convenience rather than visiting hospital.

6. In my following statement, the dates quoted are from memory, and may vary slightly to the dates of the actual events as I have not been able to retrieve all of my medical notes. I have been sent the limited notes that are held by the Cardiff and Vale Health Board Trust but these are far from complete.

2. How Infected

1. Whilst coming from a family where haemophilia was present, little was known in the 1960s about the complexities of haemophilia and how it was passed from generation to generation. In my particular case, I was the first family member to be diagnosed with haemophilia since my grandfather. Haemophilia had therefore skipped a full generation being passed down through the blood line via my mother.

2. I was diagnosed as having haemophilia A at the age of 15 months after being hospitalised at Cardiff Royal Infirmary for a severe mouth bleed after falling over. The doctors were unable to control the bleeding and I was treated with cryoprecipitate and whole blood transfusions, remaining in hospital for about 2 weeks.

3. As the severity of the bleeding was not normal, the doctors decided to test me for haemophilia and this came back positive.

4. The doctor in charge of my care whilst in hospital at this time was Dr Bloom (later to be Professor) and this was the first time my parents had met him. They always considered that Dr Bloom had saved my life on this first occasion and they had complete faith in him from then on and never once questioned anything he said or the treatment he recommended.

5. I was hospitalised on two other occasions up until the age of six. Firstly, suffering bleeding to the face and head after falling off a wall and secondly, suffering a gash to the buttock after falling on a spiked fence.

6. Between the age of 6 and 11, I was taken to hospital on three or four occasions suffering from internal bleeding in the stomach. The exact reason for the bleeding at the time was unknown but was later discovered to be the result of having developed a duodenal ulcer. On each occasion I had lost a considerable amount of blood and was treated with cryoprecipitate and whole blood transfusions.

7. As there was no treatment available to cure the duodenal ulcer and the risk of future bleeding was very high, Professor Bloom recommended that I should have surgery. The procedure was known as a Highly Selective Vagotomy and this would stem the flow of acid to the duodenum and the ulcer would heal. My parents had total faith in Professor Bloom and agreed to the surgery going ahead. The operation was carried out at the recently opened University Hospital of Wales in 1974 when I was 11 years of age. I was hospitalised for about three weeks and made a full recovery. My understanding was that I had cryoprecipitate and whole blood transfusion but my records also show that I did in fact receive factor 8.

8. I continued living a full and active life throughout my teenage years playing competitive football and rugby and doing all the things that a normal teenager would do. Unfortunately, the surgery was not totally successful and I

continued suffering from internal bleeding until the age of 23 when medication became available to control the problem.

9. One of the consequences of leading a 'normal' life was that I was more susceptible to injury than my friends and throughout my teens and into my early twenties. I had numerous bleeds into my joints, along with various cuts and bruises. I was mostly treated as a day patient at the Haemophilia Centre at the Heath Hospital Cardiff but also had a number of short stays in hospital to treat more severe bleeds.

10. I recall my mother telling me that she remembers Professor Bloom telling staff to 'give this treatment to the GRO-B boys not that one'. Indeed, Peter Collins, the Haemophilia Centre Director in Cardiff has recently openly stated that Professor Bloom had a list of what treatments could be administered to which patients.

11. With the development of freeze dried factor 8 products in the 1970s, I was taught to self-inject which meant that I could keep treatment at home and treat myself when needed. Batch numbers of bottles of factor 8 used were recorded on forms provided by the Haemophilia Centre at the Heath. Forms were returned to the Haemophilia Centre along with any unused bottles of factor 8.

12. Between the late 1970s and mid 1980s my visits to the Haemophilia Centre at the Heath Hospital became quite infrequent, mostly returning for annual check-ups with Professor Bloom at his outpatient's clinic. I attended clinic with my mother until 1982 and then on my own once I had passed my driving test. Clinic appointments always involved a blood test but results were never reviewed or discussed.

13. During this time, I have vague recollections of discussions at the clinic about having been infected with Hepatitis A and B but there was no big deal made of this. I also have vague memories of receiving vaccinations (or boosters) but I don't recall any discussions of the health implications of having been infected with Hepatitis.

14. My first recollections that there was something more serious going on was in the mid-1980s when the government launched a distasteful TV advertising campaign warning about AIDS. I also remember the first haemophiliac being diagnosed at about the same time. This caused a great deal of fear within the haemophilia community. I have no recollection of being told I was being tested for HIV or Hepatitis at this time. As I hadn't been told anything different and I was in good health, I suppose I naively thought everything was fine. This was also against a background that I had been having very little treatment in this period and was only visiting the haemophilia centre annually for check-ups.

15. I can't pinpoint exactly when I was infected and certainly there had been no suggestions of infection or discussions about the risk of infection that I can recall.

16. As stated I don't remember the exact dates, but at an annual check-up in the late 1980s, or possibly the early 1990s, I was informed that as part of the 'routine' blood testing being carried out, a new Hepatitis virus had shown up in my system. The virus was referred to as non-A, non-B (later to be called Hepatitis C). I was told that the virus acted differently to A and B and there was no cure, or vaccination, at that time. The seriousness of the virus was not emphasised and was even played down with staff suggesting that a cure would be 'around the corner'.

17. My brother was also informed that he had been infected with Hepatitis C at about the same time. He had had much less treatment than me and didn't have his first treatment until the age of 14 in 1980.

18. Additionally, it was almost implied that we were lucky as haemophilia sufferers to be infected with Hepatitis and not HIV. The feeling I had was almost that it was passed off as being a bi product of haemophilia rather than a mistake in terms of providing infected products and was almost regarded as a reasonable risk.

3. Other infections

1. I was diagnosed with cirrhosis of the liver and later liver cancer which resulted in me needing a liver transplant. I will discuss this in greater depth in the latter part of my statement.

4. Consent

1. As I have indicated there was a blind faith in the medical professionals at this time and particularly in Professor Bloom who was very well respected.

2. I knew I had Hepatitis C but I believe I was probably blocking it out and getting on with attempting to live a normal life. I would indicate however that having seen my notes and my earlier notes there is a reference in a letter from 1979 which is a disclaimer my mother had to sign to indicate that there was some risk of contamination.

3. This letter is the only reference I could see within my records to it and is almost out of context given where it is placed in my records with no other notes. I discovered I was infected at around the age of 20. I had a daughter and son born a few years later and that would suggest there was no information given regarding protected sexual intercourse.

5. Impact

1. I met my wife in 1981 and we got married in 1984. My daughter was born in 1985 and my son in 1988. As stated earlier, I can't remember the exact dates I was told I had been infected with Hepatitis C but I know we had both children so it would be definitely post 1988.

2. As a result of the Government's distasteful TV advertising campaign about AIDS, and the link with haemophiliacs being infected, there was now a huge stigma attached to being a haemophiliac. Soon there were numerous stories

in the media of families being victimised in their own communities as a consequence of their infections becoming public knowledge. Only my very close family were aware of my infection. Between us we made a conscious decision not to share this information with our wider group of friends, my employers or work colleagues. I didn't even share the fact that I was a haemophiliac.

3. The stigma of being infected played a huge part in my life during this period. My main priority was to protect my wife and children. Unfortunately, the government advertising campaign had created a mass hysteria about AIDS and there was a lot of misinformation about how the virus could be transmitted. I suppose I was 'hiding' the fact that I had haemophilia and that I had been infected with Hepatitis C created a form or denial within myself. As a consequence, I didn't really get involved in the campaigning groups that had been set up to help haemophilia victims who had been infected. I just wanted to distance myself from the whole situation and get on with my life. I wanted to keep it quiet as I didn't want there to be any impact upon my children. This is something I feel a lot of guilt about now.

4. As I have stated earlier, I have always led pretty much a normal life other than when I have required treatment for bleeding and, other than mild fatigue, I didn't feel ill during this period despite having Hepatitis C. I had very little treatment throughout the 1990s and my only contact with the haemophilia community was via my annual check-up at the haemophilia centre in Cardiff. To some extent I had become 'detached' from the whole situation. I suppose my thinking was that I was lucky not to have been infected with HIV and that I should just get on with my life and wait for the Hepatitis C cure that was 'just around the corner'.

5. Again I can't remember exact dates (probably between 2000 to 2005) but I recall my annual check-ups starting to involve discussions about 'viral load' and 'liver function tests'. The consequences of these tests were not really discussed. There seemed to be limited understanding by the doctors treating us of the full consequences of these 'viral loads' but there was clearly a link to

abnormal liver function. Again, there were no discussions about what abnormal liver function meant. It was only a number of years afterwards that I became aware that other infected haemophiliacs had started developing liver disease at this time.

6. The whole situation changed for me when my brother was informed that he had developed fibrosis (scarring) of the liver and this could soon develop into cirrhosis.

7. During this time there had been some progress with developing treatments to try and eradicate Hepatitis C but these were all at the clinical trial stage and nothing as yet had been approved by NICE for use. Due to my brother's worsening situation he agreed to enter one of the clinical trials being offered. He was in one of the first trial groups to be treated with Alpha Interferon therapy for a period of 48 weeks. Whilst the viral load within his system was greatly reduced during the treatment he failed to clear the virus and the viral load quickly returned to its former levels. The side effects were very debilitating. As well as suffering flu like symptoms for almost a year, my brother also suffered severe depression which had a huge impact on his family, his work and his quality of life.

8. Over the next couple of years my brother's condition worsened and he had now progressed to cirrhosis of the liver. He tried a further course of treatment, this time combining Ribavirin with Interferon but again this failed to clear the virus. Again he suffered the same debilitating side effects as before.

6. Treatment/Care Support

1. In the period up to 2006, I attended regular annual check-ups at the Heath Hospital's Haemophilia Centre. The viral load in my system had been gradually increasing and I had been asked by the doctors on a number of occasions if I wanted to try a course of treatment to try to clear the virus. A lot more was now known about the Hep C virus and it was now clear that liver disease would progress very quickly once fibrosis (scarring) stage was

reached. A considerable number of haemophiliacs had now died of liver disease since being infected. I was also now having regular ultrasound scans on my liver to check for abnormalities.

2. Up until this point I had made a conscious decision not to start treatment for a number of reasons. Firstly, I was feeling well, despite having the virus, secondly, I had watched my brother going through the debilitating side effects of treatment, and thirdly, I had started a property development company in 2001 and I would not have been able to keep the company going if I couldn't work. By 2006 my business was doing well and I had taken on a number of employees.

3. I was very aware of the numbers of haemophiliacs now dying of liver disease and I was also watching my brother's health deteriorating so I made the decision to start a course of treatment of Ribavirin and Interferon. This was a tough decision to make as I knew my chances of clearing the virus were below 50%. The treatment involved self-injecting interferon into the abdomen 3 times a week and taking Ribavirin tablets orally.

4. My worst fears were confirmed after a few weeks on the treatment when the flu like symptoms started. I was given a glimmer of hope after 6 weeks when the virus became undetectable in my system but this would need to remain negative for the full 48 week course of treatment. I was housebound for most of the time I was on the treatment and was only able to work a couple of half days per week. The treatment was so aggressive that I needed blood transfusions to top up my red blood cells destroyed by the Ribavirin. It was only the thoughts of clearing the virus that kept me going throughout this period. I was devastated when I started getting positive virus results halfway through the treatment but decided to push on finally completing a total of 56 weeks of treatment.

5. Unfortunately, the virus returned to its former levels soon after stopping treatment. This was probably one of the worst periods of my life and I would never have got through it without the support of my family and work

colleagues. Even after stopping treatment it probably took 6 months for the side effects to stop completely.

6. At this time, all my care and support was via the Haemophilia Centre at the Heath Hospital Cardiff. There was hepatology 'support' at haemophilia clinics from Dr Godkin but there was no access to a full-time hepatologist. By 2007 my brother's condition had deteriorated further and he was visiting clinic on a frequent basis.

7. Due to the lack of a hepatologists in Cardiff my brother was referred to a liver specialist in London by Dr Desani. I can't remember which hospital he attended but I recall he saw this specialist 2 or 3 times.

8. In November 2008, my brother was referred to the specialist liver centre at the Queen Elizabeth Hospital in Birmingham due to abnormalities showing up on his liver scans. I recall him saying that the medical team in Cardiff were suspicious that he had developed cancerous tumours in his liver. He was so relieved when he was told that despite his liver being in a poor condition, they were satisfied that he didn't have cancer. They did however state that he would probably need a liver transplant within 5 years.

9. My brother spent the next 6 months in and out of hospital with issues related to liver disease. The team in Cardiff were still suspicious that something wasn't right so they sent him for a liver biopsy. Devastatingly, this confirmed that he did in fact have Hepatocellular Carcinoma and had probably had it for 2 years given the size of the tumour. More concerning was the fact that the tumour had spread into his lymph nodes.

10. Despite all this bad news there was still hope that he would be able to have a transplant.

11. It soon became apparent that he did not qualify for a transplant under the Milan Criteria as the tumour was too large and his liver function was very poor.

12. My brother was so desperate to beat this that he paid privately to get a second opinion from a specialist at Harley Street in London. We also sought opinions from specialists in America and Europe to see if there was any way in which we could help him. We even managed to secure funding through the local health board for a life extending drug called Sorafenib in the hope that the tumour could be brought under control to allow him to have a transplant.

13. My brother lost his fight against liver cancer and died in GRO-B 2010.

14. During the period leading up to my brother's death I was informed that I had now developed cirrhosis of the liver and this was confirmed by a liver biopsy. Whilst my thoughts were with my brother and the whole family at the time, I couldn't help thinking that I was probably looking at what the future had in store for me.

15. My clinic appointments and ultrasound scans were now held every 6 months to monitor the condition of my liver.

16. During this period, further progress had now been made with new drugs to fight Hepatitis C, Telaprevir and Broceprevir. These drugs were very expensive and there was limited funding to make these drugs available. Local health Boards seemed to be fighting over cash to fund these new drugs and I was told that I would no longer be able to be treated for my liver disease at Cardiff as I lived in GRO-B and this came under the Aneurin Bevan Health Board. This seemed a ridiculous situation as I still had to attend the haemophilia centre in Cardiff for my haemophilia care. This was a very frustrating and distressing time as I had been under the care of Dr Brendon Healey in Cardiff and he was close to securing funding for the new drugs.

17. I entered the system at the GRO-B Hospital in GRO-B under the care of Dr Marek Czajkowski, a specialist hepatologist, in November 2012. I was again attending clinic having six monthly ultrasound and blood tests.

18. As Telaprevir and Broceprevir were both used in conjunction with Interferon and I did not want to go through the same experience as previous, I decided to seek alternative treatments and after much internet research I discovered that a number of centres in the UK were about to trial the 'next generation' of Hep C drugs. St Mary's Hospital in London was one such centre that was about to undertake phase 3 trials for one of the new treatments so Dr Czajkowski referred me to see Professor Thursz. Unfortunately, my liver function results were too high for the criteria set by the pharmaceutical company so I was not selected.

19. In April 2014 at one of my routine scans the radiographer discovered a suspicious lump in my liver. I was referred for a contrast dye MRI and was told that I had developed a tumour. Further tests confirmed it was cancerous. Whilst this was devastating news, I was told that the tumour was quite small (2.5cm) and it had been caught very early. I was also told that the only cure was a liver transplant. It was explained that the tumour had to be kept under 5cm to qualify for a transplant so I was immediately referred for Radiofrequency Ablation to burn or shrink the tumour. This was carried out in July 2014 at the GRO-B Hospital in GRO-B and involved an overnight stay in hospital.

20. As stated earlier, progress with finding a cure for Hep C was moving at some pace and in August 2014 I successfully applied to be placed on a trial for a new drug Sofosbuvir. This was to be taken in conjunction with an already approved drug called Ledipasvir. The combination of these drugs was quite ground breaking in that I had cleared the virus within 12 weeks with very minimal side effects. This was a huge bonus as my Hepatitis C would infect a newly transplanted liver.

21. I was referred to the Queen Elizabeth Hospital in Birmingham for assessment for liver transplant in September and, following numerous tests over the following months, was placed on the liver transplant waiting list in February 2015.

22. I continued having routine scans and in April 2015 it was discovered that the tumour had regrown. I was admitted once again to the GRO-B for Microwave Ablation in May 2015 to again burn or shrink the tumour.

23. This was a very stressful period for myself and my family, just waiting for a phone call and wondering whether the call would come in time. I felt the best way to cope during this time was to continue with as normal a life as possible and continued working right until the day of my transplant.

24. I eventually received a call at 2.30am on the 19th August 2015 from the transplant centre at Birmingham and was told to get to Birmingham as quickly as possible. I had the transplant later that day. There were some complications during the operation and I ended up losing a lot of blood. The surgeons were unable to stem the bleeding so I was put on blood transfusion and sent to intensive care. It took a full day for the surgeons to be satisfied that the bleeding had stopped. I was then taken back to theatre to be sewn up. I spent a total of 8 days in intensive care before being transferred to the ward. This was a very stressful time for my family.

25. I was released from hospital after 3 weeks but then had to travel back to Birmingham twice a week for tests to ensure my body wasn't rejecting the liver. This was a very difficult period whilst my body adjusted to the immunosuppressant medication that I would now have to take for the rest of my life. I suffered quite bad side effects in the early stages of recovery due to the high levels of anti-rejection drugs and steroids I was taking. It was during this period that I didn't think I would be able to return to work and it was only after about 3 or 4 months that I started to realise I could make a full recovery.

26. Throughout this period, I had incredible support from my wife and my children. My son even travelled to Birmingham twice in one day on a number of occasions.

27. I was off work for seven months returning in April 2016. My employer was incredibly supportive and I was lucky enough to be paid in my absence as my salary was protected by an insurance policy.

28. When I was diagnosed with cancer this was the first time I had actually told my employer about my medical condition. Obviously I had to explain that I had been placed on the transplant waiting list so that preparations could be made for my impending absence. Most of my colleagues knew very little about the situation other than it was a bleeding disorder but they were incredibly supportive and have been since.

29. My health has been excellent since returning to work and I even underwent a full hip replacement in December 2016 to solve a long term hip problem. I have returned to a normal life except for the fact that I take 10 anti-rejection tablets per day and will have to take these for the rest of my life. I suffer from some side effects because of my medication but they are all manageable. I have headaches quite frequently and my memory and concentration are not what they used to be.

30. I am now three years' post-transplant and my prognosis is positive. However, it is always in the back of my mind that statistically the 5 and 10-year survival rates post liver transplant are 72% and 60% respectfully. I am always aware that I could suffer from acute rejection at any time and that I may need another transplant in the future.

31. My outlook on life has changed slightly in that I am far more conscious about financial security for my family such as pensions and life insurance. I have been unable to get life insurance or mortgage protection insurance for the last 10 years which has been refused due to the Hepatitis C.

32. Previously when I was self-employed I had seven hundred thousand in Keyman insurance cover but again this was also refused upon renewal due to my Hepatitis C. Additionally, as a company director my fellow directors are entitled to five times their salary on death whereas my policy is limited to one

times my salary. Therefore, there are potentially massive financial implications for my family resulting from my infection.

33. From a bleeding disorder perspective, I have always received excellent care and support from the haemophilia centre in Cardiff. I also believe that the 'ground roots' medical staff have done all within their power to help the haemophilia community through the devastation that the contaminated blood crisis has left.

34. However, senior staff within the NHS and government after government have failed the community in their duty of care from the very start.

a) First of all, the crisis would never have happened in the first place if senior NHS staff and politicians had heeded the warnings about self-sufficiency of blood products. Obviously, money was a bigger priority than people's lives.

b) Secondly, they were far too slow to respond when the scale of the crisis started to unfold. Instead they decided to try to buy people off and sweep the problem under the carpet.

c) Thirdly, even though the scale of the crisis has been known for a number of years they still continue to resist providing adequate funding and resources to help and compensate those that have been affected.

35. I have never been offered any counselling or support of any kind. Because of the stigma attached to being infected, and my determination to protect my family, I didn't share my problem with anyone other than close family and very close friends in the early days. This has made me a very private person and I have always had a tendency to bottle things up. Despite my infection now being known to a much wider group of friends and work colleagues, I still find it difficult to talk about my situation. For this reason, I have requested anonymity during the inquest.

36. I also received correspondence from the haemophilia centre in Cardiff stating that I may have been exposed to vCJD as part of the blood products I received. Whilst this was a standard letter that was sent to all haemophiliacs as this is still a possible risk, this was not well managed and again caused anguish within the haemophilia community.

7. Financial Assistance

1. In terms of payments, I received stage 1 payment of £20,000 from the Skipton Fund for being infected with Hepatitis C. This was an ex gratia payment and was subsequently topped up to £50,000.00.

2. I then received a stage 2 payment of £45,000 from the Skipton Fund when I was diagnosed with cirrhosis of the liver.

3. I now receive a payment of £18,500.00 per annum via the Wales Infected Blood Support Scheme.

4. It has always been emphasised that payments are ex gratia and not compensation.

5. I would also point that there is complete disparity between payments received in Wales, England and Scotland. This appears to be a postcode lottery and an equal system should be implemented across the UK. Payment to spouses should continue upon the death of an infected person as per the scheme in Scotland.

8. Other Issues

1. I would confirm at this point that I have twice requested my medical records. I have received 2 disks but these are far from a complete record of my notes in my view.

2. I have gone back to query this but I have been told that is all that they have.

Statement of Truth

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

Signed.. GRO-B .....

Dated 19/02/2019