Witness Name: GRO-B
Statement No: WITN2053001
Exhibits: 0
Dated: 28.11.2018

WITNESS STATEMENT OF GRO-B

INFECTED BLOOD INQUIRY

Section 1: Introduction

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

2. I am retired and live in GRO-B with my second wife who I married in 1999. GRO-B GRO-B GRO-B

Section 2: How infected

3. I was diagnosed at age 6 with moderate severity Haemophilia A. In the 1950s and 1960s I had whole blood and plasma transfusions and 'stypven' viper venom on several occasions. I was treated at various hospitals in GRO-B

GRO-B. I recall going into hospital quite often but I do not know exactly how many times I received these treatments during this period.

4. I was at university in GRO-B, this is where I think I was infected. I was a patient of the Haemophilia centre in Cardiff and was treated by Haemophilia consultant Dr Arthur Bloom, after whom the Cardiff Haemophilia centre is now named. I received blood products there on at least 3 occasions, probably more.

5. I was given cryoprecipitate or factor 8 in Cardiff in 1969 for a swollen knee, in late 1971 for a cut arm and in early 1972 for a single tooth extraction. Around two weeks after my tooth had been removed I started to feel unwell. I returned to the dentist for a follow up appointment. He told me that I had jaundice and that I should go to the Haemophilia centre. A doctor at the Haemophilia centre told me that I must go home and stay in bed and avoid alcohol.

6. Two days later the same doctor walked from the Haemophilia centre to my student lodging nearby which I thought was a rather strange thing for a hospital doctor to do. He told me that I had to go into an isolation hospital in Cardiff for some tests. I asked him where had the jaundice come from and he told me that I had caught a virus after having the tooth extraction, this is how he put it. At the isolation hospital I was told that I had Hepatitis B and that I was infectious. I was a patient in an isolation ward for six weeks. I only saw the doctor once more when he came to the isolation hospital. I do not recall any other doctor seeing me. I had no treatment and I cleared the Hepatitis B 'naturally'.

7. I was directly infected with HBV and HCV from blood products for treating Haemophilia. Which of the infusions in 1971 or 1972 caused HBV was never

explained to me. I think I was infected with Hepatitis C in Cardiff in 1972, maybe at the same time as the Hepatitis B. When I applied to the Skipton Fund I obtained a letter from Dr Peter Collins, Consultant Haemotologist at the University Hospital of Wales who is the current Clinical Lead of the Arthur Bloom Haemophilia Centre in Cardiff. In it he states "*...I have little doubt that he contracted Hepatitis C from treatment given in Cardiff in March 1972...*"

8. While in Cardiff I did manual work most weekends for a friend in London. I had to go to hospital in London a few times while I was there: on one occasion I put a nail through my foot and on another a chisel in my hand. I can't remember whether I had cryoprecipitate or factor 8 on these occasions.

9. I do not know what was ever said to my parents about the use of blood products when I was a child. I first had cryoprecipitate or concentrated factor 8 in 1969 on my 21st birthday. On that and all subsequent occasions no nurse or doctor giving me blood products has ever warned me about any risks.

10. In the mid 1970s I had a friend who worked in a government laboratory in Cardiff which was part of the Blood Transfusion service. She warned me about Hepatitis being in the imported clotting products. When I reminded her that I had already had Hepatitis B and I thought I couldn't get it again, she said the Hepatitis she meant was a different type which didn't have a name, but which they were pretty sure was coming from imported blood products. She told me that I better be careful because I could still get it. Indeed, I almost certainly had already got it. By that stage I had already adopted a very negative attitude to anything being injected into me. I was rather wary of this magic clotting agent stuff especially after being in hospital with Hepatitis B. I decided that I would

avoid it if I could. I was 'lucky' to have only moderate severity Haemophilia and I have tried to avoid all clotting products completely.

11. I was only informed that I had 'nonA-nonB' Hepatitis in the early 1980s. I had by this time married a fellow student who I had known since 1970 and we were working overseas. A doctor had referred me to a liver specialist; I can't recall being told the specific reason for the referral. I had some blood tests over a period of a few months which showed elevated liver numbers.

12. When confirming 'nonA-nonB' Hepatitis the liver specialist told me that I would certainly infect my wife and any children with the virus. I was also told there was no treatment. This was a major shock to me and my wife whose younger sister had died of liver failure from acute Hepatitis only a few years earlier. I was not given any other information or advice about managing the virus.

13. I think I must have completely forgotten what my friend from the government laboratory had told me about a 'different type' of Hepatitis in the mid 1970s. I was stunned, I thought I can't have it, I had already had it. I was shocked. I could not believe that I was hearing this after I had been avoiding blood products like the plague. I can now see that I had probably been given it about 10 years earlier,

14. My wife and I had only been married for three years and we were trying to start a family. Suddenly this was not an option for us.

15. It subsequently transpired that the information I had been given about me infecting my wife and any offspring with 'nonA-nonB' was completely wrong. But this was of no help at the time. My wife and I discussed the situation for

months but could see no solution. We separated and a few years later we divorced. I have never had any children.

16. I should emphasise that in the 5 year period between the likely date of infection (1972) and when I went overseas, I avoided going anywhere near a Haemophilia centre and hence did not have any blood tests in the UK, so I cannot hold any UK medics to blame for not detecting and informing me about 'nonA-nonB' sooner.

Section 3: Other Infections

17. I do not believe that I have received any infections other than HBV or HCV. My local Haemophilia centre has informed me that I was unlikely to have been exposed to vCJD since I was not in the UK in the relevant period.

Section 4: Consent

18. I do not know if I have been treated or tested without my knowledge or consent, or without being given adequate information or for the purposes of research.

Section 5: Impact

19. My trust in medical treatment for Haemophilia has disappeared completely. Being diagnosed with Hepatitis C just reinforced my previous concerns, and ever since I have been determined to have the minimum possible treatment. I have pulled some of my own teeth out to avoid having Haemophilia treatment and I would rather rest swollen knees or other joints for extended periods than have clotting agents. In my view, that includes the so-called 'safe' recombinant

agents. That's how I have chosen to react mentally to being given HCV. My distrust extends to General Practitioners who seem to have little knowledge about HCV or its treatment, and who are quite negative towards people like me even though they know we were given Hepatitis C via contaminated blood products.

20. I don't know whether the various mental and physical problems I have come from having had HCV for many years or the three year-long courses of treatment I've had to try and clear the virus. I think it is more likely the courses of treatment.

21. The first treatment was overseas in the mid 1990s which comprised a year long course of interferon injections 3 times a week. It didn't work. In the UK I had a second year long course of Interferon and Ribavirin treatment in 2010/11 which didn't work and finally a third year long course of Interferon and Ribavirin and Boceprevir in 2012/13 which cleared the virus.

22. I had to pay about £7,000 for my first course of treatment overseas, because my private medical insurance specifically excluded anything to do with Haemophilia or Hepatitis. I had no significant problems with getting the second and third courses of treatment in the UK. There was an insignificant wait of about a month or so because of what was described as 'budgetary constraints'.

23. I am not aware of any other treatments that were available.

24. The treatments have had a serious effect on both my physical and mental health. The physical effects during my first course of interferon-only treatment in the mid 1990s were significant. I had flu like symptoms, headaches and

nausea, but the main effects involved ongoing insomnia and tiredness during the day. I took sleeping tablets but they were ineffective and I still have insomnia today. I was falling asleep during the day and this and other mental issues had a significant effect on me.

25. I developed a persistent dry cough which went away slowly when the course ended but it came back with a vengeance during my second and third courses. It seemed to reduce when I finished the third course but now it seems to have become a more permanent feature. The cough is so bad at times that I have to avoid speaking because I start coughing. In January this year I coughed so badly that I caused a large bleed in my abdomen. I have been to see various medics about it and have recently had some x-rays but haven't had a follow up appointment yet. I also had heart palpitations during the first course of Interferon which recurred during the second and third courses. I've kept quiet about them because it was a requirement to have my heart checked before each course of treatment and I was determined to get on the courses. They still happen now.

26. The treatment has had a significant effect on my mental health. I was a Consultant Engineer in a company I founded in the late 1980s. My role involved a great deal of travelling, the writing and presenting of project reports for clients, and giving presentations at local and international conferences. As the first course of treatment went on it was as though I had suddenly become a different person. I normally worked six days a week – sometimes every day. But I became more and more tired and began to do less and less. I had to get other partners to take over my travel activities and then had to reduce my work hours drastically. I just could not stay awake during the day and I was getting anxious about letting other people down.

27. The worst was when I actually lost all confidence in my abilities to do things and I had to stop working altogether. I had been divorced from my first wife for a number of years. I was living on my own and I actually became too frightened to go outside my flat. I didn't even know why or what I was frightened of. When the course ended I gradually recovered some of my 'normal' self and went back to work but I still got very tired and had to reduce the amount of hours I worked. Things never got back to what they had been.

28. Eventually, in 2004, I was forced to retire from the company I had founded. In accordance with a Shareholder's Agreement, I was required to sell my entire shareholding in the company to the remaining directors/shareholders. The money I received helped me to purchase a house and for some savings which I have used to supplement living costs. When I sold my shares, the company had a total staff compliment of about 15. In the period since then the staff compliment has risen to over 100 and the associated turnover and net worth has risen dramatically. It is a very successful company and I have suffered a significant loss of annual income and the benefit of an associated rise in the value of my shareholding when I was at the peak of my career.

29. I have not been employed since 2004. I lost all confidence in my abilities and sense of self-worth, this still continues today.

30. I have always kept quiet about my Haemophilia, most of my friends do not know about it and none of them know about my Hepatitis. I worked in a company once where the blood transfusion people used to come and spend a day taking donations. I had to make sure I was always out of the office or on a day's holiday in order to avoid any awkward questions.

31. I had already learnt to keep my mouth firmly shut about Haemophilia for various reasons, one of which was the Headmaster of a school I was joining the next day who announced my imminent arrival and told the entire school assembly not to pick on me. I was black and blue by the end of the first week. So it was second nature to keep my mouth shut when AIDS arrived in the mid-1980s. What was strange was that although I didn't have HIV, I had to keep quiet about having Haemophilia. At that time people with Haemophilia were being stigmatised because the general public seemed to think anyone with Haemophilia must have AIDS. This situation had a very bad effect on me and it still affects me today. Since then, I have shut myself off from mixing socially and making new friends because I know I would have to lie about myself. I still have this view.

Section 6: Treatment/Care/Support

32. I have not faced any difficulties or obstacles in obtaining treatment and care. Counselling has been mentioned to me but I have never pursued it.

Section 7: Financial Assistance

33. In 2010 I met with a Haemophilia consultant after being referred to a hospital for a tooth extraction. This was the first contact that I had had with a Haemophilia centre since returning to the UK six years earlier. The consultant did not mention anything to me about the Skipton Fund.

34. I only found out about the Skipton Fund when I started my second course of treatment later that year. I was asked whether I had received the stage 1

payment, when I said no I was told I must be the only Haemophiliac in the country not registered with Skipton. I completed the forms and gave them to the liver treatment centre. The forms were passed on to a Haemophilia consultant who knew nothing about me and in order to register with Skipton I needed to obtain further information.

35. I went to the centre in Cardiff where I had been treated in the 1970s and met with Dr Peter Collins, Consultant Haemotologist at the University Hospital of Wales who is the current Clinical Lead of the centre. He said he was "sure that I was given Hepatitis C in Cardiff" and wrote the letter referred to in Section 2 of this statement. I forwarded this and further medical information to the Skipton Fund and my application was accepted.

36. In 2011 I received the Skipton stage 1 lump sum payment of £20,000, and in 2016/17 I also received a total payment of £6,020 from the Skipton Fund. Between 2013 and 2017 I received a total of £21,167 from the Caxton Foundation. I now receive payments from EIBSS only and in 2017/18 I received a total of £6,710.

37. I was registered by the Skipton Fund as being an "English" claimant since my application form stated I had been given blood products in London as well as Cardiff. Apparently when there is uncertainty in the place of infection, Skipton simply put claimants in the place of residence when registering. Skipton did not inform me of their decision and I only found this out in 2017. I am registered with the 'English' EIBSS. One would assume that the four nations would adopt the same set of rules, but they certainly didn't and even now they are all different.

38. I have been working with the Contaminated Blood Campaign (CBC) for several years and have carried out a lot of research into the discrepancies between the different payment schemes for those infected by contaminated blood. When I first got involved with CBC the one thing that struck me was that there was so much discrimination against those infected with HCV compared to those infected with HIV. In 2011, after the Archer report, the government had every opportunity to pay people infected with HCV fairly. However, all they did was to create the Caxton Foundation. This was such a miserly 'charity', especially when compared with the Macfarlane Trust and the Eileen Trust. In 2012, when Caxton was started, Caxton paid out only 15p for every pound that the Macfarlane trust paid to victims.

39. Personally, I think these discrepancies and discrimination are unacceptable. I also think that means tested payments are particularly unfair. I think that they must stop all means testing of infected victims and other beneficiaries.

<u>Section 8: Other Issues</u>

40. My hospital records for the period that I was receiving blood products are very thin. I struggled to obtain information from the National Haemophilia Database but eventually I was provided with a few documents which detail the dates that I received cryoprecipitate and factor 8 in Cardiff. However it is rather strange that the one record that is missing is when I had clotting agent for a tooth extraction in March 1972 which is when I was hospitalised with Hepatitis B.

41. I expect the Inquiry to carry out a full investigation covering all of the terms of reference. I would like the Inquiry to uncover the truth about what caused the disaster, who was responsible, who ordered the destruction of personal medical

records and government documents and who ordered and who carried out the cover-up over the last thirty or forty years.

Statement of Truth

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

Signed GRO-B

Dated 27 NOVEMBER 2018