Witness Name: GRO-B

Statement No: WITN1516001

Exhibits:0

Dated: March 2019

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 my date of birth is GRO-B 1948 and I live at GRO-B GRO-B

2. I live with my husband and we are both retired. I am disabled due to poor health. I suffer from Chronic Fatigue and muscular/joint issues as a result of Sjogrens Syndrome. I also have severe Osteoarthritis, which has developed as a result of my infection with Hepatitis C and the treatment I received. My husband is my carer.

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

Section 2. How Infected

4. I was born with a hereditary bleeding disorder; Von Willebrand disease, Type 2M. I have always considered the disorder to be more of a nuisance than a danger, I suffer from a moderate form of the disease. I rarely need medication to help with clotting, except in the event of trauma or major surgery.

5. I was first treated with Factor VIII in 1981 at Southampton General Hospital, where I was treated by Dr GRO-D This was a one-off treatment to prevent bleeding with minor surgery.

6. I am certain that I was treated with Factor VIII without being given adequate information. At the time I was undergoing a minor procedure to remove a steel wire from my foot, the wire had been inserted the previous year as part of a major procedure. During the previous procedure I had been treated with cryoprecipitate. I can remember being surprised in regards to the simplicity of administrating Factor VIII and I stated this at the time. At no time, prior to the treatment, was I told which product I would be treated with, I certainly wasn't told of any possible risk of infection. Had I been warned I would have refused treatment.

7. As a result of receiving blood products, I have contracted Hepatitis C (HCV).

8. In 1985, my 17 year old son (who also has von Willebrand Disease and, coincidentally, was also treated with Factor VIII in 1981) and I were told that we should both be tested for HIV because we had been identified as possibly infected through Factor VIII. There followed a harrowing wait for the results. To our great relief the results returned negative in both cases.

9. In December 1994, my son told me he'd been tested for Hepatitis C at his last haematology appointment and the result was positive. I remember being very shocked and upset. I knew very little about Hepatitis C at the time and thought that he would soon die. He was told that he must have been infected by contaminated Factor VIII in 1981 when undergoing an appendectomy.

10. Following this diagnosis I was contacted by the haemophilia centre because my son had asked if I should also be tested for Hepatitis C.

11. After being tested I was diagnosed with Hepatitis C. I was told by a nurse who said it was a fairly harmless disease and the risk of us infecting partners was almost non-existent. I remember her telling me that I would probably die with it, rather than of it. I do not remember being advised about alcohol consumption at that time. I now know that the information I was given was wholly inadequate. I believe that the truth about the severity of the disease was being played down.

12. I think I should have been called in for a test in 1991 when the Hepatitis C test first became available. I feel angry that they knew everyone who had been exposed to Factor VIII was more likely than not to be infected and yet they did not bother to test us until three years later. In fact, even prior to the time that a test became available, they knew we were at risk and our liver function should have been regularly monitored. To my knowledge, this did not happen. This is so wrong.

Section 3. Other Infections

13. I have very poor health and believe, rightly or wrongly, that it's possible I have been infected with unknown pathogens. From a psychological point of view, it is irrelevant whether I am infected with anything else because the constant wondering and speculating has had an impact on my health due to anxiety.

Section 4. Consent.

14. I am unsure if I have been tested without my consent. I do however believe I was treated without consent as I was not given full or adequate information when receiving Factor VIII.

Section 5. Impact

15. It was not until some years later that I realised my infection with Hepatitis C explained why I had suffered bouts of abnormal fatigue since I had been treated with Factor VIII. The fatigue had been passed off by my GP as perfectly normal for a mother with a busy life. It wasn't until years later that I also learnt that Hepatitis C is associated with depression. I now realise that the virus explains why I suffered a few years of the most dreadful depression starting around the time that I was infected.

16. The mental and physical effects of being infected with HCV are huge. One compounds the other. The physical effects feed the mental anguish and vice versa. My last fibroscan showed a fibrosis score of 8.8, which is edging close to cirrhosis. I suffer from chronic fatigue and this has an impact on all aspects of my life. At times the fatigue is so severe that I am unable to do anything other than sit around or lie down. I often have to let people down and cancel arrangements, this makes it difficult to maintain relationships with my family and friends. Of course, in turn this feeds the mental effect that HCV has on me and there have been times when I have felt quite depressed and hopeless.

17. After suffering from Chronic Fatigue in conjunction with joint and muscle problems for many years, I was finally diagnosed with Sjogren's syndrome in 2016. My Consultant Rheumatologist at the time, Professor Edwards, confirmed that he believes the Sjogrens was caused by my HCV infection. My health has continued to deteriorate since I was diagnosed with Sjogren's Syndrome.

18. In 2017, x-rays revealed that I had severe osteoarthritis in both hips and knees and therefore needed joint replacements. My rheumatologist told me that Sjogrens was not the cause of my osteoarthritis, but that it would accelerate its progression. It is now well acknowledged by medical professionals that HCV causes Sjogrens, I therefore believe that my osteoarthritis is caused indirectly by HCV. However, this has never been acknowledged by the NHS and I have had to wait for my surgery along with everyone else.

19. I reached the stage where I could barely walk 20 yards and required a wheelchair or mobility scooter if I needed to travel further. I have undergone one hip and one knee replacement surgery in the last twelve months which had given me a little more mobility. Major surgery of this kind is a huge challenge in my state of health. Each operation brings on a major flare of the Sjogrens and brings on increased fatigue and disabling pain in multiple joints and muscles.

20. Prior to treatment with Interferon/Ribavirin in 2009, my HCV genotype was recorded as Type 2/3. After the treatment, it was described as Type 3. I suspect that I was originally infected with two genotypes and the treatment killed off the Type 2 but not the Type 3. The hepatology nurses have tried to say that the reason I was told I was infected with HCV type 2/3 is because it wasn't possible for them to distinguish between the two. I do not agree with this and I believe they are trying to cover up the extent of my infection.

21. In 2009, I underwent treatment with Interferon/Ribavirin. This was a very difficult period of my life. After approximately one month, the treatment made me so unwell that I ended up collapsing in the shower one morning before work. After this incident I was too weak to even walk down my stairs and had to be signed off work for six months. In an attempt to reduce the side-effects of Ribavirin my dosage was reduced, this only made a slight difference and I was still too ill to work. I was 61 at the time and had deferred my state pension, intending to retire at 65. I managed to return to work for a few months after

stopping treatment but I was not fit to work and therefore retired before my 62nd birthday. Within a short time of stopping treatment, the virus returned, so the whole thing was in vain.

22. I now realise that the Interferon treatment should never have been prescribed to me, given that I was already showing strong signs of Autoimmune Disease. I have found evidence in my medical records that doctors had previously advised against me receiving Interferon treatment. I bitterly regret being persuaded by GRO-B at Southampton General to undergo the treatment. I clearly remember explaining that I wasn't badly affected by the HCV and that I was reluctant for the treatment. I remember the words he said to me to this day. He told me "*it will catch up with you one day, you know.*" Thus, he scared me into agreeing to the treatment.

23. In 2016, Professor Edwards, Consultant Rheumatologist, advised that my HCV should be treated with one of the new Generation Direct-Acting Antivirals (DAAs). He told me that clearing the HCV infection might improve the Sjogrens and also told me that Sjogrens can be treated with immunosuppressant medication but this is inadvisable whilst infected with HCV. I had already been turned down for funding on numerous occasions by the liver clinic at Southampton General on the grounds that my liver fibrosis score was not high enough to meet the criteria set by NHS England. I asked Professor Edwards to support me with a letter explaining why I needed the treatment. He wrote a letter for me and made a strong case as to why the NHS should pay for my treatment. The request was once again turned down. To my dismay, I was offered a second course of Interferon/Ribavirin. I cannot begin to describe my feelings about this. To this day, I still feel the hurt about this particular insult. The injustice that I was offered the very medication that had made my health deteriorate so much was only made worse by the 'take it or leave it' attitude. I appealed the decision and the outcome was the same as before, an offer of Interferon/Ribavirin. I was absolutely devastated that I could be treated so badly.

24. The anguish of fighting so hard to get NHS funding had a profound effect on my health and caused my mental state to deteriorate. In January 2017, after a huge amount of worry and research, I decided to stop fighting for the NHS to treat me with respect or compassion. I made the decision to buy generic versions of the medication I needed through an internet buying group, from a pharmacy in India. Out of desperation to improve my failing health, I took this decision against medical advice from every doctor I saw. I paid £1,300 for a course of Daclatasvir and Sofosbuvir. My desperation outweighed my fear in regards to the

effects this medication could possibly have on me. Fortunately, the risk paid off, by the summer of 2017 the HCV was no longer detectable.

25. My diagnosis of severe Osteoarthritis was made soon after completion of the HCV treatment, so I had the prospect of multiple joint replacements to contend with. Because of my medical history, I thought it would be reasonable to ask for some priority for the operations, this request was turned down. My first hip replacement was in March 2018, more than a year after the x-rays were taken showing severe osteoarthritis. My right knee was replaced in December 2018 and I am now on the waiting list marked 'urgent' for the left knee. All this, on top of the Sjogrens and Hep C, is extremely difficult to cope with for both myself and my husband.

26. At no time since my diagnosis with HCV have I been treated with any sense of priority by the NHS. When I was first diagnosed with HCV I was told that I would need to transfer to a dentist in the infectious diseases unit at Southampton General Hospital because of the danger of infecting other people. After my first appointment, this dentist was moved to a clinic in the red light district of Southampton. At appointments, I was obliged to share a waiting room with prostitutes and drug addicts. I was in my forties and working at the time. I therefore had to make my dental appointments late in the day so as to avoid time off work. When winter came, my appointments were after dark. There was no car park at the clinic so on-street parking was the only option. I remember feeling very afraid finding myself walking alone in the red light district after dark. Because of this I stopped attending a dentist at all until I finally plucked up courage to approach a private dentist who agreed to treat me despite my HCV infection.

27. HCV has had a significant impact on my private, family and social life. The fact my son has also been infected by contaminated blood increases the impact. My son has cirrhosis and of course this is a huge worry for me, adding to the worries about my own health. It was a dark time for my family when he was diagnosed with cirrhosis. My son also has other health problems linked to HCV so my family are in a constant state of worry. In an obscure way, I am conscious that I have something in common with my son that perhaps is seen by my daughter as a bond that she does not share. This makes me uneasy about discussing mutual health problems with my son when my daughter is also present.

28. My social life is now very difficult because there are so many days when I am very unwell. My friends have to accept that I often have to cancel arrangements. None of my friends

fully understand the full extent of my illness, possibly because I tend to play it down. I feel I have to play it down because I have so many things wrong with me on a day to day basis and I am mindful that they might think I am a hypochondriac, or worse still, that I am making it up. In fact, I fell out with a lifelong friend recently because she repeatedly implied that she thought I was making things up about my ill health. The systemic nature of the autoimmune disease that I have been left with because of HCV and Interferon treatment means that my health problems are very complex. I think it would be impossible for anyone other than my husband to absorb all the facts.

29. I am very conscious of the stigma surrounding HCV and therefore do not like to tell people of my condition. This makes it very difficulty to explain why I am in such ill-health.

30. Since the time of my diagnosis in 1995 my work life has been affected. Soon after being diagnosed with HCV I was sacked on the basis that I had 'too many problems.' These problems were my infected status in addition to the worry caused by my son's infected status. I admit that I found working full-time very tiring prior to being diagnosed but I had not realised there was good reason for my fatigue.

31. In 1998, I made the decision to work part time. I worked part time until I retired. In 2001 I was working as a teacher in a further education college. I was offered a full-time post with added responsibilities and a substantial increase in salary. Unfortunately I had to turn down this great opportunity because I knew my illnesses would prevent me from doing the job to the standard I was capable. As well as this loss of potential earnings, this added to the sense of inferiority HCV had given me.

32. My life is blighted by this sense of inferiority. I'm not the same person I used to be, I don't feel like a normal person. My life has been soiled and damaged. When I found out the truth reading through scripts from the Archer inquiry, I was angry, upset and horrified. To this day I am haunted by the thought of murderers and rapists queuing to sell their filthy blood in a US prison. The thought that there are remnants of these vile people inside my body makes me shudder. Even now, it makes me feel dirty. The fact their blood has resulted in my permanent disabilities and poor health adds to my sense of shame.

33. Up until the time of starting Interferon treatment I had not revealed my HCV status to my employer. However, as I was aware that the side-effects were likely to impact my work, I felt obliged to be honest with the college. I was told I must not reveal my infection to the

students and when I returned to work after my long period of sickness, my absence was explained as being a result of me undergoing an aggressive type of treatment for an undisclosed illness. I felt bad about this as I believe my students thought I had cancer.

34. The financial effects of HCV are significant. For the 10 years that I was teaching I could only work part-time so my earning potential was over 50% less than it would have been if I had been healthy.

35. Living with a chronic illness and subsequent disability not only compromises earning and pension potential, but incurs additional living costs. In my case the extra costs have been extensive. I am required to pay extra premiums on travel insurance, this increases more as my illness progresses. I now need mobility aids such as a mobility scooter, wheelchair, crutches and walking sticks in order to remain some-what independent. I have had to have a raised WC and walk-in shower installed. I have had to make adaptations to the steps leading to my house in addition to handrails. I can no longer drive manual cars and have to drive an automatic transmission. In addition to these extra functional costs I have had to pay a lot of money on taxis and other expenses for my numerous hospital appointments. I have to travel from GRO-B for most of my appointments.

36. The illnesses caused by my infection have had a significant impact on my husband. As the years go by and my health deteriorates further, I am able to do less. My husband has to carry the load in regards to housework, gardening and shopping whereas before we would both do these tasks. In addition, I am able to do less in regards to our social life. We used to go for walks together, go dancing and go out for meals in the evening. He now either has to do this alone or not at all. It has been some years now since we have been able to have a holiday together because most of the time I am not fit to travel. When we have managed a holiday they have been ruined by me being ill and having to seek medical assistance. Nowadays, we only go away for a few days at a time and never more than a short distance from home. This still proves difficult as we are limited to hotels that provide adequate facilities for my disabilities.

37. My husband takes me to my numerous hospital appointments and a lot of our time and money is spent travelling to hospitals and waiting in waiting rooms. When I am at my worst he has to push me around in a wheelchair. I am sure it is difficult for him.

38. Other family members are also affected by my illnesses and mobility issues; I regularly have to cancel pre-planned arrangements. It would be impossible for me to look after my grandchildren because I just don't have the energy required for looking after children.

Section 6. Treatment/Care/Support

39. I have never been offered counselling or psychological therapy. At the time I was diagnosed I felt dirty, ashamed and marginalised. Routine blood tests brought further shame and humiliation. The papers that contained my medical information would have bright yellow stickers attached. The stickers were emblazoned with the words 'warning, danger of infection' in bold letters. I remember I would attempt to conceal the stickers while in the waiting room. I suffered the shame and embarrassment of watching the phlebotomist put on two sets of gloves just to take my blood. I would then have to watch them attach the stickers of shame onto the vials of my blood.

40. I really believed the NHS might have felt the moral duty to treat contaminated blood victims with a little more respect, perhaps even treating us with a measure of priority; this has never been the case. Sjodrens Syndrome is a systemic disease that requires consultations and investigations with multiple specialists. Since becoming very unwell in 2016, I have paid for private consultations with a neurologist, rheumatologist and urologist because of the long waiting lists in order to see an NHS consultant.

41. I am aware that those who have suffered from infected blood products are entitled to 6 counselling sessions through the Hepatitis C trust. I am also aware that 6 counselling sessions are currently available to anyone under their local GP. In other words those who have been affected are receiving no additional help in order to deal with the psychological impact of being infected through contaminated blood products.

Section 7. Financial Assistance

42. I received £20,000 from the Skipton Fund in November 2004.

43. I became registered with the Caxton Foundation for discretionary support in October 2012 and subsequently applied for various grants for household repairs, boiler maintenance,

home improvement, travel expenses to and from hospital etc. In addition I have also received the winter fuel allowance. After 1 April 2016, I successfully continued applications for hospital travel expenses. Applications for other grants were sometimes approved but often turned down by the Caxton administration.

44. In November 2017, the regular payments and discretionary grants administration was passed over to NHS Business Services Authority (NHSBSA). At that time the NHSBSA continued to honour my applications for hospital expenses, however I found their requirements for proving income for other discretionary grants too onerous and invasive of my privacy. For that reason I did not apply. I was not prepared to give out the extensive personal information that they required from me. They then cut funds towards my hospital expenses. I am required to travel for my surgeries and pre-operation assessments, this means I usually have to stay overnight in a hotel in order to make my appointments. If I miss my appointments my surgeries would have to be rescheduled so I am left with no other option but to pay myself. This can cost me hundreds of pounds for each appointment.

45. In February 2018 my application for Special Category Mechanism (SCM) payments was accepted and my annual payments increased to about £12,000.

46. In April 2018 the SCM payments increased to £18,000 per annum.

47. In August 2018 my application for top up payments was accepted; increasing my payments by £134 per month.

48. The regular payments are an improvement compared to when my only access to assistance was the discretionary support scheme. I found applying for assistance very demeaning and often became stressed and angry about having to go through the onerous application process. I was made to feel like I was begging for help.

49. When Caxton were administering their discretionary payments scheme I frequently became very distressed by their arbitrary decisions and demands. I have so far found EIBSS no better in that respect.

50. When I applied for the initial £20,000 payment from the Skipton Fund, I seem to remember signing a waiver agreeing that I would not seek further compensation.

Section 8. Other Issues

51. For over 3 years from 2011 I was heavily involved in campaigning as GRO-B GRO-B When I wasn't doing that, I contributed to the campaign by writing letters to ministers and MPs as an individual. The frustration of being fobbed off again and again by the Government was soul destroying at times. Some of the affected people were quite abusive and the infighting between victims as well as the relentless fight with the government became too much when my health became worse.

52. I was involved in US litigation about 20 years ago but had to give up because there was no record of the Factor 8 batch that was supplied to me by Oxford. The only record in my medical notes is that it was issued by Oxford.

Anonymity, disclosure and redaction

53. I confirm that I do not wish to have anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

54. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed……GRO-B…………

Dated…………5/4/19……………………