Witness Name: GRO-B
Statement No: WITN1514001
Exhibits: WITN1514002-7
Dated: January 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 GRO-B. I was born on GRO-B and I live with my husband of 20 years. GRO-B

2. **This statement has been prepared without the benefit of access to my full medical records.** I managed to obtain some records, although a considerable amount of information was missing and some entries were incorrect. Some records refer to me as GRO-B (maiden name) and GRO-B (my ex-husband's name).

Section 2. How infected

3. I have Von Willebrand's Disease which was diagnosed when I was aged approximately 11 following an acute appendicitis procedure, during which I bled heavily.

4. **Exhibit WITN1514002** is an extract from the National Haemophilia Database dated 30th October 2018 which provides an incomplete list of the dates on which I received Factor VIII.

5. In 1974 I received a number of bottles of Factor VIII and a whole blood transfusion during a caesarean section operation when delivering my first child. I also received Factor VIII in 1976, following the delivery of my second child.

6. I underwent dental work in approximately 1978 and 1979 which necessitated further treatment with Factor VIII.

7. I required treatment with Factor VIII in 1982 when I underwent a subtotal hysterectomy. I underwent the finalisation of this procedure on 8th August 1990. **Exhibit WITN1514003** is an extract from my medical records confirming that I received multiple bottles of Factor VIII during, and directly after, this procedure.

8. The hospitals where I received Factor VIII and whole blood transfusions were:

    a. GRO-B (1974)
    b. The Middlesex Hospital, London (1976)
    c. St Thomas' Hospital, London (Late 1970's)
    d. Brighton General Hospital, Brighton (1982 onwards)

9. My main Consultant was Dr Kenny, who has now retired, and my current Consultant is Dr Hill.

10. I was infected with Hepatitis C as a result of receiving contaminated blood and contaminated blood products and I strongly suspect that I was infected in 1976 or 1982. **Exhibit WITN1514004** is the first page of a letter dated 6th April 2018, confirming that I have Hepatitis C Genotype 1B.

11. I received no information or advice regarding the risks of receiving either Factor VIII or whole blood transfusions. This was extremely disappointing and surprising because a number of my medical records were stamped in bold with the words "**HEPATITIS RISK**". **Exhibit WITN1514005** is an extract from my medical records confirming this. I have also seen records prior to 1986 which had this warning stamped on them.

12. In or around September 2017, I received a telephone call from the Haematology Department at Worthing Hospital asking me to pop in and see them. I was due to undergo some dental work so I thought that it would be to double check that everything was in order for this. Dr Hepburn, Consultant Haematologist, sat me down and said *"your blood tests have all come back. Did you know that you have Hepatitis C?"*. My immediate thought was *"don't be stupid you have got the wrong person's test results because I only associated Hepatitis C with needles and drug addicts"*. I was in utter shock and it was true; I had Hepatitis C. I am still struggling to process this news as I have not had very much time to process matters, given my relatively recent diagnosis.

13. After this visit, a nurse arranged for me to be seen at Worthing Hospital instead of Brighton General Hospital, because she felt that I would be more suited to their Hepatitis clinic due to the nature of patients that attended the Brighton clinic. She also told me that I would need a liver scan because I could already have cirrhosis.

14. My GP telephoned me shortly after I had received the bombshell diagnosis to ask if I was okay and I told him that I was very far from okay and knew nothing about Hepatitis C and that I was shocked and confused.

15. This prompted my GP to send someone from the Health Department at Worthing Hospital to speak with me. Soon after I was seen by two nurses at my home and they tested me for diabetes which confused me. One of the nurses told me to be very careful with blood spillages and this was especially relevant to me due to my frequent epileptic fits which sometimes resulted in

complete strangers mopping up my blood whilst I have been unconscious on the ground. I was very scared as I would not want to put any one in danger and I was more scared as I had already, unwittingly, put complete strangers at risk; not to mention my wonderful husband. Aside from being told to clear up blood spillages with bleach, I am of the view that I was not given sufficient information to understand and manage Hepatitis C.

16. I am so angry and upset that no one bothered to tell me that I had Hepatitis C until only relatively recently. This belies belief especially because so many of my hospital records have been stamped with "**HEPATITIS RISK**". I am now extremely distrusting of the medical profession as it took them decades to tell me about my infection.

Section 3. Other Infections

17. I believe that I was put at risk of vCJD.

Section 4. Consent

18. I was tested without my knowledge and therefore without my consent. I again refer to **Exhibit WITN1514005** which also confirms that I was being screened for HTLV. I was never told that I was being tested for this.

19. **Exhibit WITN1514006** is an extract from my medical records dated 24th July 1990 which states "*HIV antibody = NOT detected*". This is another example where I was tested without my knowledge and therefore without my consent.

20. I was also treated without my knowledge and therefore without my consent. **Exhibit WITN1514007** is a letter dated 17th September 1993 from Dr Kenny, Consultant Haematologist, to Dr Stalker confirming that the Hepatitis B vaccine course had proved ineffective and that it would be worth trying the booster and a repeat antibody test would be performed in 2 months time. I had no knowledge of this and was therefore unable to consent to the same.

21. I believe that I was used for the purposes of research because Dr Kenny took sole charge of my care to the extent that he would not allow the nurses to take my blood; it was always him. I used to think that he was incredibly involved with me as there were very few female Von Willebrands patients but in retrospect, I believe that he used me for the purposes of research.

Section 5. Impact of the Infection

22. Being diagnosed with Hepatitis C has ruined my life. At the same time, I now have a diagnosis which explains the symptoms which I suffered over the years.

23. I had a great career as a manager of residential care homes but I suffered from extreme exhaustion to the point that I was unable to continue in this role. I also suffered from a lack of concentration, lack of co-ordination, insomnia and serious depression.

24. The depression has been very difficult to deal with and I feel incredibly sad when I consider how difficult it has been for my husband, who is aged 75, to deal with my diagnosis of Hepatitis C. This is complicated by the fact that I suffer with epilepsy. My wonderful husband looks after me whenever I have a seizure. During a recent seizure I collapsed and became impaled on a broken coffee cup which necessitated that my husband cleared up the blood and took care of things. It is distressing and depressing to think that I have put my husband at risk of contracting Hepatitis C.

25. I told my husband about my Hepatitis C diagnosis as soon as I found out which was in September 2017. He has been incredibly understanding, supportive and calm. He was tested and thankfully had not contracted the virus. He is now aware that he has to be very careful when clearing up any blood spillages. However, it is a constant worry for both of us as he was diagnosed with vascular dementia 5 years ago so we support each other as best we can. He is a very kind, gentle, wonderful and old fashioned man, who

has been fantastic but is still dealing with the aftermath of my diagnosis. We are both struggling with the bombshell news; so much so that my GP has arranged for us to have some counselling early this year.

26. I also worry that I infected my ex-husband who passed away from liver cancer. There is not a day which goes by when I don't question whether it was me who unwittingly infected him. In fact, my sister actually asked me if it was me who killed him. This was deeply upsetting. I dare not mention any of this to my children because I am petrified as to how they may react. My relationship with my children is already somewhat strained due to their reaction to the news of my diagnosis.

27. I told my children about my Hepatitis C status in September 2017. They both thought that it was a junkies' disease and sat there in total dismay. They were disgusted with me and they rarely come and visit now; which was in stark contrast to how things were prior to my diagnosis. Furthermore, they will not allow the grandchildren to eat, or stay overnight, at my house. This has hurt me deeply; more so than the diagnosis itself.

28. My sister had a similar reaction upon hearing the news, from me, that I had Hepatitis C. She actually said *"that's disgusting, you don't do anything like that"* after which she asked me directly whether I had caught it via sexual contact. She has been quite distant and has not made contact with me since finding out.

29. I did not confide in any of our friends and gradually, as I stopped accepting invitations, those invitations declined. Hepatitis C made me extremely introverted and socially isolated to the point that I no longer recognise who I was prior to my diagnosis.

30. I commenced the treatment, consisting of Viekirax and Exviera, for Hepatitis C in February 2018. Prior to this, the haematology nurse, made me feel very guilty about the cost of this treatment and I found this distressing, even more so given the mode of my infection. She advised me that the hospital could

only select 3 patients in the area each month to commence treatment. I was petrified as I knew that I had to have the treatment otherwise my life would be in grave danger. I asked her how many people there were, like me, on the waiting list. She replied that there were very few and that most of the patients were drug addicts so I stood a fairly good chance of being chosen.

31. The side effects of the treatment were horrendous. I suffered with complete urine retention which the doctors have still not been able to resolve. I have endured irreversible muscle damage and I have to self-catheterise every day and this will continue for the rest of my life because it is inoperable.

32. During the treatment, my depression became almost intolerable and I would cry at anything and everything. My insomnia worsened and I had extremely large and painful mouth ulcers. There were days when I was sat on my couch, unable to move with extreme sickness and vomiting. I could not even consider going to my studio, at the end of the garden, which was sad as mosaics were my solace and something that I loved to do. It was me; it was my thing and it had been so cruelly taken from me.

33. The haematology nurse requested that I email her to keep her abreast of the side effects I was experiencing. I quickly realised that this was of no benefit to me because no one contacted, or assisted, me with managing the side effects. This was only of benefit to the pharmaceutical companies who I believe used this as a method of data capture. The nurse admitted to me that this treatment was designed to be a "*one size fits all*". I was a petite woman and I believe that I therefore felt the side effects more resolutely. I was told that the doctors could not reduce the dose because the treatment would be futile.

34. The doctors stopped my treatment after only 8 weeks. It was meant to last for 12 weeks but I was advised that my Hepatitis C was undetectable at the 8 week stage. However, I am still undergoing blood tests every 3 months to test my viral load. My next tests are due next month and if the results are satisfactory, I will be moved to a 6 monthly testing regime.

35. Prior to being diagnosed with Hepatitis C, I underwent chemotherapy for breast cancer. I had numerous courses of chemotherapy and the doctors could not understand why my cancer kept returning in such an aggressive form. The specific type of cancer which I suffered was hormone-led and DNA tests were conducted in a bid to try and understand the cause because it was not hereditary. I am ANA positive and I am convinced that my immune system has been severely compromised by Hepatitis C.

36. I have generalised osteoarthritis, osteoporosis, iron deficiency anaemia and Vitamin D deficiency. I also suffer from steatorrhea which means that the muscles in my bowel do not work and I have to suffer the indignity of using a machine once per day to empty my bowels.

37. In relation to financial effects, I had to give up working due to complete exhaustion. In order for me to progress my career I needed to complete a number of additional courses which was extremely difficult given the exhaustion, which I now believe was caused as a direct result of the Hepatitis C. At this stage of my life, I was still with my ex-husband who was unemployed and we struggled financially.

Section 6. Treatment/care/support

38. I experienced difficulties with regard to commencing my Hepatitis C treatment. There was a delay in receiving this treatment because I had to be weaned off my epilepsy drugs. In addition, I experienced a further delay because the hospital would not start the treatment until my dental work had been completed.

39. I was due to see a maxillofacial dentist at Worthing Hospital and I duly attended the pre-op in readiness for this treatment. Shortly after the pre-op I received the devastating news of my diagnosis. I then received a letter confirming that my dental treatment had been cancelled. I could not believe it and was beside myself with worry as I was waiting to start the Hepatitis C

treatment. My mouth was covered in abscesses and there was considerable damage to my gums and the texture of the bone in my mouth had turned into what I can only describe as "*honeycomb*". I telephoned the dentist's secretary who advised that I could not be seen for a couple of months. I was shocked and I complained to the Haematology Department; with the outcome being that the dentist was forced to treat me because I urgently required the Hepatitis C treatment.

40. Therefore, my husband and I duly attended the dentist for my morning appointment. We were seated in a separate room to the other patients and I felt that I was being treated differently. A nurse took some blood from me and we were left waiting for a fairly long time. One nurse then advised me that my blood results were back and that I would be called in shortly. Another nurse then came into our room and said that my blood results were not back yet. I ended up being last on the list for the dental procedure that day despite the fact that I was booked in for a morning appointment and by then had waited all day. I knew that my blood test results had come back fairly promptly and that they were just using this as an excuse. It was obvious that they considered my Hepatitis C to be a risk and they did not want to clean the theatre after treating me in readiness for a non-infected patient.

41. When I finally entered the theatre, the dental nurse asked me if I had any cuts or open wounds. I showed her a small cut on my shoulder which I had sustained as a result of falling during a seizure. She fetched an enormous Elastoplast, which was far too big for my cut, and firmly stuck it on. I understand that certain precautions have to be taken but I was treated very badly as a result of my Hepatitis C which I found upsetting, distasteful and so obviously wrong.

42. After receiving this awful treatment, I ended up taking the stitches out myself. I did not want to endure being treated like this ever again. I was in disbelief at the fact that the people who were meant to be looking after me had such negative attitudes towards me and I found it devastating.

43. I am also disappointed with the lack of care which was shown to me when I was diagnosed with Hepatitis C. I felt very alone and ignored by the medical profession. I had to actively seek direct psychological support from my GP, which was extremely hard for me because this was at a time when I felt unable to do very much at all.

Section 7. Financial Assistance

44. I found out about the Skipton Fund via the hospital at the time of my diagnosis. I received the Stage 1 payment of £20,000 in 2017.

45. I also receive £333.32 monthly and this began in 2017.

46. The hospital advised me that I may be able to apply for the Special Category Mechanism payments (SCM) but my application was unsuccessful.

47. I successfully applied for a top up payment of £340 per month in 2018.

48. Additionally, I received a winter fuel payment of £500 in December 2018.

49. The process of applying for these payments was difficult and I sought the assistance of the Citizens Advice Bureau (CAB). I was impressed with the staff at the CAB which was in stark contrast to my experiences with the staff at the Skipton Fund, who I found to be rude and unhelpful.

Section 8. Other Issues

50. I am a member of the Factor 8 campaign group. My lovely husband took me to London at the end of 2017 where I was able to get involved and support several protests as part of this campaign group.

51. The medical profession knew me and they knew where I lived. There were and are not many female Von Willebrand patients. I want to know why I was not contacted when I have lived in the same area for all of my life. I am also extremely angry that the medical profession did not even glance at my medical records and notice that they had been stamped in bold with the words "**HEPATITIS RISK**". Given these stark facts I wonder whether they did in fact know that I was infected and purposely let me suffer, unknowingly and alone.

Anonymity, disclosure and redaction

52. I confirm that I do wish to apply for anonymity and if my anonymity can be protected I would like to give oral evidence to the Inquiry.

GRO-B

Statement of Truth

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

Signe GRO-B

GRO-B

Dated 27/02/2019

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