Witness Name: GRO-B
Statement No: WITN1499001
Exhibits: WITN1499002-3
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. I was born on the GRO-B 1964 and I live at GRO-B GRO-B with my wife, GRO-B and our two teenage children. I am by occupation a self-employed tradesman.

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

3. I have GRO-B Von Willebrand's Disease. I have suffered with severe nose bleeds from childhood and bruising and I was diagnosed with Von Willebrand's Disease at 6 or 7 years old. I was treated at the GRO-B GRO-B under the care of Dr Helena Daly amongst others (I do not recall the names of the consultants). I am now under the care of GRO-B

4. I became infected with the Hepatitis C Virus (HCV) as a result of being given contaminated blood products.

5. I was treated with Factor VIII (FVIII) on a number of occasions as I was growing up. I had a number of dental extractions and sustained an injury playing rugby when I was 15. I have been told that I could have contracted HCV from any number of treatments.

6. I believe my medical notes to record that I was first tested as HCV positive on 13th February 1991. I have been unable to obtain my medical notes and records but I was given that date by a hepatology consultant looking at my notes a few years ago.

7. I was not told that I had HCV until the following year (1992). I was told by Dr Daly in the hospital corridor/foyer. I do not recall what we were talking about but I remember Dr Daly saying to me as we parted "by the way, you should know that there is a slight trace of Hepatitis C in your blood".

8. I did not know what to make of this at first. I was not given any further information from the hospital and I was not told how to manage or understand the infection. It was only when I heard about HCV through the media and news in the following months that I realised it was a lot more serious than I initially thought. I remember a listener on the Jeremy Vine radio show recounting how her father died within two weeks of learning he had HCV. I was scared. I did not know what would happen to me and I did not know what could be done to help me. I remember thinking "I could be in real trouble now".

9. GRO-C Neither my parents, my sister, nor myself were ever given any advice about the risks associated with FVIII treatment. We do however recall a comment made by a doctor treating GRO-C GRO-C when she had a horse riding accident many years ago when I was young. The doctor said "this blood is from the men of the Russian Army

and there is no chance of you getting anything from them". I did not know then to what he was referring.

10. I was referred to the hepatology department in or around the end of 1992. I was told of a big conference at the hospital and that it would be a good idea for me to attend it. It was from this that I learnt about the risk of transmission and the importance of clearing up blood, using bleach and to be careful with razors, toothbrushes etc.

11. I was not provided with any further information from the hospital and/or offered counselling. I was told that a liver biopsy was not an option for me due to my bleeding disorder. I was told that HCV treatment was unlikely to be successful for me because my particular HCV genotype was difficult to clear.

12. I believe I should have been told of my HCV diagnosis much sooner. Dr Daly was very good at her job. She was very competent and good under pressure. I believe Dr Daly to have made herself unpopular at Truro Hospital by informing patients (like me) about their infected status. I refer to **Exhibit WITN1499002** being an article about Dr Daly's suspension from work in 1992 and reinstatement three years later. I also refer to **Exhibit WITN1499003** being an article about Dr Daly's demanding clotting agent be heat treated as far back as 1985 when she worked for the Blood Transfusion Service.

Section 3. Other Infections

13. I have been informed that I am at risk of CJD because I may have received a contaminated batch of blood products.

Section 4. Consent

14. I attended hospital appointments every six months. I was told that the blood taken at my appointment was to check my blood clotting levels. The doctors would also check my stomach which I thought strange at the time. I now believe that they were checking my liver.

15. I was tested for infection without my knowledge and consent. I was never told that I was being tested. The first time I was aware that I had been tested for HCV was when I was informed by Dr Daly that I had a 'trace of" HCV in my blood.

Section 5. Impact of the Infection

16. When I learned that I had HCV my world fell apart. I had a partner at that time and a two year old daughter. The HCV diagnosis ruined our relationship. My partner was worried that she would catch HCV as would her children. When we split up I lost my home, my family and the life I had come to know. I spent the next two and a half years living in a bedsit. I suffered with depression and was prescribed antidepressants. I had no counselling, back up or support. I had very little hope for the future as (initially) there was no treatment available thought to be effective for me.

17. Being infected with HCV has left me self-critical and reclusive. I used to be far more sociable and outgoing. I lost interest in going out and wanted to hide myself away. That feeling has never really left me. I met my wife GRO-B 17 years ago. She is a tremendous support to me. It was a risk starting a family together. We are even now ever vigilant about the risk of sharing towels and keeping my razor and toothbrush away from the family. My nose bleeds can last for as many as four days and when this happens my family has to be really careful and GRO-B and I make sure everything is meticulously clean.

18. Around 14 years ago, I began clearing treatment with a 12 month course of Interferon and Ribavirin. I had to inject myself with interferon several times a week and take tablets. The treatment and side effects were bad and my test results showed that the treatment was not working. It was stopped at 6 months. I lost weight and my hair fell out. I was prescribed anti-depressants for depression as my mood was plummeted. I would have been better off not having the treatment.

19. The treatment side effects (still ongoing) are memory loss, insomnia, lack of focus and speech problems. My memory loss and lack of focus is like a brain fog, a feeling of being really blank-minded.

20. My current state of physical health is that I have a lot of joint pain and problems having developed rheumatoid arthritis from HCV. I have chronic fatigue, a lack of energy and insomnia. I am constantly on edge and am aware that I could sink into a lower depressive state if I am not careful. I used to enjoy fishing and watching rugby. I am disinterested now. The wind has been taken out of my sails.

21. Being infected with HCV has had a significant impact on my work and has had financial implications on myself and my family. I continued working during my treatment, but really struggled to manage due to the side effects I was experiencing.

22. I worked for 12 years as a plumber for a housing society in GRO-B fitting kitchens and bathrooms. I had all the benefits of a well paid full-time job to include holiday pay, sick pay and occupational pension contribution payments. I carried on working there throughout my clearing treatment but could no longer continue after I had an operation GRO-B 5 or 6 years ago. In working as a team, I was always concerned about my HCV infection at work and the possibility of cross infection through blood on tools. I would panic if I cut myself. I did not tell my colleagues about my HCV status. In my experience, people do not treat you well if they know you are infectious. You can tell by the way people talk that I would be stigmatised if they knew.

23. I now work as a GRO-B on a self employed basis without the benefits I had before. The nature of the work I can take on has been hugely affected because of rheumatoid arthritis, joint pain and physical exhaustion. My earning capacity has been adversely impacted as a result.

24. I have lost out on alternative job opportunities, like mining and working on an oil rig as full medical disclosure and a medical examination is required.

25. I pay as much as £70 per month for for life insurance. I have to do so in order to protect our mortgage.

Section 6. Treatment/care/support

26. I was told that I could not have a liver biopsy because my bleeding disorder. I had to wait many years for a fibroscan. I believe a fibroscan should have been undertaken sooner.

27. I had to wait for about 10 years before having a second round of clearing treatment because of my nightmare with the first round of treatment. The side effects of the second tablet-based treatment were not as severe and I hope it will be a success.

28. I have not received any counselling or psychological support. I believe that counselling would have been beneficial to me as I have struggled mentally at times.

Section 7. Financial Assistance

29. I received a Stage 1 Skipton Trust payment of £20,000 approximately 14 years ago and then no financial assistance for years.

30. I then received monthly special category payments (to include a discretionary payment allowance) through the Caxton Fund because I had developed rheumatoid arthritis. The haematology nurse helped by verifying the blood level evidence required. She helped me complete this application and provided my blood levels as medical evidence for this.

31. The process is a cruel one and makes you feels like you are begging, jumping through hoops for any payment you are entitled to. You have to be able to meet a very specific criteria. Moreover the grants are now means-tested.

32. The whole system is very wrong and puts a lot of people off. There is probably a pot of money sitting there somewhere completely untouched.

Section 8. Other Issues

33. There are significant risks associated with having an HCV infection to your family. To withhold a diagnosis from a patient is not only unethical and unprofessional but negligent in terms of the care owed to the families of the patient. On behalf of all those infected, we trusted our health care professions and just wanted safe factor, not dirty blood.

Anonymity, disclosure and redaction

34. I confirm that I wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I would not like to provide oral evidence to the Inquiry at the hearings.

Statement of Truth

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

Signed... GRO-B ....

Dated 12/1/2019