Witness Name: GRO-B
Statement No.: WITN3614001
Exhibits: WITN3614002-
WITN3614005
Dated: 18.11.2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1962 and my address is known to the Inquiry. I make this statement in connection with the care and treatment provided to me in respect of the management of my anaemia by the Royal Devon and Exeter Hospital (RDEH).

2. Whilst I am happy to provide the Inquiry with the information set out in this statement in the hope that it will assist, I would like to state at the outset that I wish for my statement, once it has been read by the Inquiry, to be anonymised and to remain anonymised. The Inquiry team will appreciate that there is a stigma attached to being infected with hepatitis C, and although the hepatitis C contamination was beyond my control, if this was made public it would potentially have an

adverse effect on my business. In the event that the Inquiry team is unable to guarantee an anonymity, I would like to withdraw my statement.

3. I am married and live with my husband GRO-B: H We have two children GRO-B, both of whom are now grown up and living independently. I am the owner of a restaurant and catering business in Devon. I work at the restaurant full time.

Section 2. How Affected

4. Up until early 2000 I had always been a fit, healthy and active person.

5. In 1988 I became pregnant with my first child, GRO-B. During the pregnancy I suffered with severe bleeding and consequently developed anaemia. I recall that on two occasions I had such severe bleeding that I was at risk of having a miscarriage albeit there was never a need for a transfusion during this time. Fortunately GRO-B was born fit and healthy.

6. In GRO-B 1991 I had my second child, GRO-B. There were fewer problems during this pregnancy and things generally went to plan.

7. In 1992 I became pregnant for a third time. Unfortunately, complications arose and I was diagnosed as having an ectopic pregnancy. I was advised to terminate the pregnancy at an early stage. I was admitted to RDEH for the pregnancy to be terminated. I recall that prior to the pregnancy termination procedure, I was told that because of my previous history of anaemia and bleeding, I should undergo a blood transfusion in order to "safeguard" against excessive bleeding from the operation and any complications thereafter.

8. Having now had the opportunity to review some of my medical records, I note that I was given the blood transfusion on 28 May 1992 before undergoing the procedure on 3 June 1992. A copy of these records are attached and labelled **WITN3614002.**

9. I recall very clearly that I felt uncomfortable about this blood transfusion and wondered whether it was in fact necessary to have it. I felt that the decision was out of my hands and that I was obliged to follow the doctor's advice.

10. Initially after the blood transfusion I felt well within myself and therefore very rarely needed to visit my GP. However, a few years later (in and around October 1999) I started to develop problems with my skin, namely when I exposed my skin to sunlight it would react violently, breaking out into a rash that resembled crocodile skin, becoming very irritated and inflamed. This reaction was baffling, particularly as I grew up in GRO-B before settling in the UK in 1985 and I had never experienced anything like this before. Sadly, as a consequence of these problems I have been unable to tolerate being out in the sun for long periods.

11. Although I was very troubled by these problems with my skin, I carried on as usual. In and around early 2000, I noticed that I was feeling increasingly fatigued and had also developed occasional hair loss. I also suffered general aches and pains, continuing migraines and high blood pressure. During the period of having these symptoms, I had a very busy and stressful job developing a new restaurant and retail centre from design ton an award winning complex, and therefore I put these symptoms down to the stresses of modern life. My general attitude in life has always been to never complain and soldier on through adversity.

12. Accordingly, I ignored the above symptoms and put them down to the stress I was going through. In and around 2013 I noticed that my body was bruising very easily, but again as I was lifting/moving tables and chairs around at work I dismissed the bruises as being of any concern and assumed that I must have a tendency to bruise easily. In the summer of 2017 during a long hike through Europe, I suffered more adverse reaction to the sun which consisted of burning rashes and

broken skin. During the trip I noticed that I felt much more exhausted than usual and I seemed to bruise continually.

13. I was becoming increasingly concerned about the symptoms that I was experiencing and so at the beginning of September 2018 I visited my GP. The GP suggested that I should have blood tests to investigate what was going on. I was due a routine smear test around this time and therefore at the same time I took the opportunity to also have my blood sample taken for the necessary blood test investigations.

14. The day after my blood sample was taken, I received an alarming telephone call from a member of staff at RDEH. The member of staff advised me to "drop everything" and make my way to the hospital immediately. At the time of the call I was at work and on my own and although this was far from ideal as I had customers who were in the middle of eating their meals, I had no other option but to immediately close the restaurant.

15. When I arrived at the hospital I felt very anxious and scared. A few minutes after I arrived, I was seen by Dr Moosa, a haematology consultant. Dr Moosa explained to me that the normal range for platelets in the blood is between 150 and 400. The level of concern is below 100 and the recommended level for safe surgical procedure due to the risk of bleeding is between 50 and 70. I was told my platelet count was 10. Therefore Dr Moosa gave me steroid injections immediately to raise my blood platelet count. A letter dated 26 September 2018 addressed to my GP, Dr GRO-B, confirms that my platelet count was only 10. A copy of the letter is attached and labelled **WITN3614003.**

16. After further investigations were carried out, I was diagnosed with an autoimmune disease, namely Idiopathic Thrombocytopenic Purpura (ITP). Essentially this means that my immune system mistakenly attacks and destroys my platelets, which are cell fragments that help blood to clot. I was advised that in adults, this may be triggered by

infection with HIV or hepatitis and therefore it would be necessary to take blood samples to investigate what the infection was. Accordingly on 26 September 2018 I was tested for hepatitis B, C and HIV and subsequently I was told that the results were negative.

17. For the low platelet level I was put on a course of steroids, namely Prednisolone 60mg for about 2 to 3 weeks. Initially the Prednisolone did help raise my blood platelet count to 50, which was an acceptable level, however over the next few months, when the steroids decreased the blood platelet count gradually decreased to. Therefore, the clinicians involved with my care regarding the low platelet count told me that the ITP should be treated with steroid injections, namely Romisplostim also known as N Plate and that the steroid injections treatment would most probably continue for the rest of my life or I'd face the risk of a serious bleed as a result of some small trauma. The side effects of the steroids included muscle cramps, numbness and chronic fatigue. Completing a day's physical work was challenging and exhausting.

18. I was very concerned about what was happening to me. I was extremely worried and anxious about how I would manage with my daily routine and work. My anxiety was further affected by the vagueness of the diagnosis, so much so that I insisted that the 26 September 2018 virology screens be re-checked. I thought that the doctors may have missed a condition such as lupus given that the symptoms are very similar. Accordingly the virology screens were re-checked on 7 January 2019, and Dr Moosa detected that the results showed I was positive for hepatitis C, not only as an antibody but as a live virus. A copy of the letter is attached and labelled **WITN3614004.**

19. When the haematologist told me that I was hepatitis C positive, I was shocked, puzzled and very scared. My understanding was that a person was at risk of contracting hepatitis C through using contaminated drug needles, casual sex or through direct blood to blood contact. I was not and I am not a person that did any of these things,

and therefore I could not figure out how or when I could have contracted hepatitis C. From 1988 onwards the only person that I have ever had sexual contact with was my husband H and he did not have hepatitis C. As such there was no plausible explanation for me having contracted hepatitis C, although I did fear that it may have been from the blood transfusion that I had all those years ago.

Section 3. Other Infections

20. None that I am aware of.

Section 4. Consent

21. In the early 1990s I do not believe I was given sufficient information about consent. The doctors explained to me what they thought should be done, i.e. transfuse two units of blood and I trusted that they knew what they were doing and giving me the best advice. I also did not really feel I had any choice but to accept that advice. I cannot comment on whether I was given the infected blood for the purpose of research but the fact that my mild anaemia was treated with a blood transfusion, it seems unnecessarily, is very alarming.

22. The transfusion was administered without any explanation or advice on the necessity of the procedure or the potential positive or negative consequences. There was little to no discussion at all. It was as if the decision had already been made and I had to sign it off for consent. That's why I felt a bewildering uncertainty about the whole event. The emotional impact of being in that situation in the first place was distressing.

Section 5. Impact

23. I underwent a FibroScan of the liver on 18 March 2019 and the result of the scan correlates to F2 fibrosis, fortunately the scarring which has developed thus far, at this stage is not cirrhosis or cancerous liver cells.

24. The impact of being infected with hepatitis C has physically and mentally drained me. The physical effect of having the hepatitis C infection has meant that my body is constantly in a battle trying to supress the effects of the virus day after day, month after month and year after year. This has now resulted in my immune system effectively attacking my body to kill the virus. At the moment the clinicians involved in my care do not know the extent of the long term damage. The previous results showed the platelet level had stabilised but no determination of success could be made within a two year recovery period, which takes us to 2021.

25. Due to chronic fatigue I have missed out on family occasions over the years, and have not been able to participate in sporting events. I've also had to limit my exposure to the sun.

26. The HCV infection has caused rheumatoid arthritis in my joints causing continuous pain and discomfort. The fatigue, muscle pain and joint pain that I had been presenting with for the previous decades, was almost certainly the onset of rheumatoid arthritis as a direct consequence of the virus.

27. My mental suffering has been very much in silence because of the stigma which is associated with being infected with hepatitis C. For example, it is a common perception that a hepatitis C infection is of a person's own making, usually by having casual sex. This has prevented me from speaking to other people about the treatment, the infection and my experience.

28. In addition I have also had the strain of keeping my hepatitis C infection status as hidden as possible from the local community, extended family

and most friends, as this could destroy my business. I have spent decades dreaming about creating this business and in the last few years I have worked extremely hard putting my dream into reality. I repeat my request for anonymity because of the stigma that is associated with hepatitis C infections and the ways that it is contaminated. My statement, the documents which I have exhibited to this statement or anything which could potentially identify me must remain anonymous. The anger which I feel for having been infected with hepatitis C through being given contaminated blood is considerable. For me to then be “ashamed” of it would be intolerable.

29. The infection has an ongoing impact. Whether or not the virus will be eliminated in these few years from treatment, it has left my body with a weakened immune system. A system that is in danger of being overwhelmed from less serious infections.

30. The emergence of the coronavirus pandemic highlights the fears and anxieties that people in my situation now feel. From this transfusion and subsequent infection, I am now in the category of most vulnerable and in real danger if I were to contract the covid-19 virus.

Section 6. Treatment/Care/Support

31. As soon as I was diagnosed with hepatitis C, I was put on a 12 week course of Zepatier to tackle the hepatitis C virus. Following on from the Zepatier treatment, the initial results are promising to the best of my knowledge and the ITP has also improved. I understand that my current blood platelet count is something in the region of 100. However, the long term damage to my system is uncertain.

32. I was presenting to the doctors with the symptoms of an infection which warranted investigation i.e. low platelet levels, raised liver proteins in blood and chronic fatigue, but unfortunately I had to wait for over a decade for the necessary investigations to be carried out. Further,

when the investigations process finally began, I was let down again by the fact that the correct blood results were not spotted the first time round. As a result of this failure, I was consequently treated with ineffective treatment.

33. Further, when I discussed the viral treatment and explained to the clinician that I was very concerned about the delay in starting the same, I was deeply shocked at the response, which was '*...there is <u>no 'rush'</u> to begin the viral treatment...*' I was told that the infection has been in my system for thirty years and a few more months would not make a difference. This was truly upsetting to hear and for me every second made a difference. Knowing that I was living with a live virus which could cause damage to my liver and consequently lead to acute liver failure and subsequently require a liver transplant was truly terrifying.

Section 7. Financial Assistance

34. In May 2019 I made an application to the EIBSS for financial support. After the application was submitted, it took the EIBSS 30 days to inform me that my application was unsuccessful. In their very brief response they stated:

> *"Applications can only be authorised where there is evidence on the balance of probabilities that infection took place prior to September 1991..."*

A copy of the letter dated 4 July 2019 is attached and labelled **WITN3614005**. This decision was inevitably very upsetting and seems very unfair.

35. I feel that it is very unreasonable that the EIBSS did not feel able or willing to exercise some discretion to make an exception to grant financial assistance to me given that the medical records confirm I was contaminated with hepatitis C through a blood transfusion. I do not

understand why the fact that this occurred in March 1992 meant that I am not entitled to some financial assistance. I would like to ascertain whether there was a possibility of infected blood still being in circulation after the date set by the EIBSS, as this date is arbitrary.

Statement of Truth

I believe that the facts stated in this witness statement are true I understand that proceedings for contempt of court may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief in its truth.

Signed GRO-B

Dated 18|11|2020