

# ANONYMOUS

04 DEC 2018

Witness Name: GRO-B  
Statement No.: WITN0319001  
Exhibits: Nil  
Dated: 21/11/2018

## INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 September 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, GRO-B will say as follows: -

### Introduction

1. My name is GRO-B. My address and date of birth are known to the inquiry.
- 1.1. I am married with two sons and I work as an Approved Driving Instructor.
- 1.2. I confirm that I do not wish to be represented by a Solicitor and I am happy for the Inquiry team to take my statement. My wife and son were present when this statement was taken.
- 1.3. I make this statement as a haemophiliac infected with Hepatitis C genotype 1b virus, following administration of infected blood products, namely Factor VIII. In particular, I will state how I was infected, how the Hepatitis C virus has affected me, the treatment I received and the impact it has had on me.

### How Infected

### Background

2. I was born with haemophilia A and my level is 0.10 IU/MI. The lower the level the more severe the haemophilia.

## ANONYMOUS

- 2.1. My family and I did not know I had haemophilia until I was around 15 or 16 years old. This was around 1974 to 1976 (I am unsure of the exact year).
- 2.2. Prior to the discovery, my parents had noticed that I took longer to heal than other children. If I had an injury, I always had to apply pressure to the wound with my thumb to prevent bleeding. I did not take any blood products to prevent the bleeding at that time.
- 2.3. There were a series of events that led to the discovery of my haemophilia.
- 2.4. My brother was admitted to the ENT Department in Lewisham Hospital to have his tonsils removed. The doctors treating my brother noticed that he would not stop bleeding following the operation and because of this, they tested him for haemophilia.
- 2.5. Following this test, my brother was informed by the hospital that he was a haemophiliac and that my mother was a carrier of the haemophilia gene.
- 2.6. As my mother was a carrier, my brother was told that all her sons are likely to have haemophilia and that any daughters would be carriers. Luckily for my brother and I, we have had only sons and so there are no more carriers in the family of the haemophilia gene. The haemophilia is not in either of my sons.
- 2.7. After my brother discovered he had haemophilia, I was called in for the same test and was also informed that I also had it.
- 2.8. My haemophilia means that minor injuries can lead to serious bleeding. During my younger years, I frequently had minor injuries as I played football for a local team and also worked as a bricklayer. When I suffered from these injuries, I went to Lewisham Hospital to receive Factor VIII and it was administered by a doctor. I cannot remember the amount given.
- 2.9. I was also given Factor VIII by the hospital to take with me to a trip to India; however I never had it administered abroad as I was always very careful not to sustain any injuries when I was there.
- 2.10. I received Factor VIII every six months or so in the mid-1970s when I played football regularly. I stopped playing football when I married at the age of 21. This is because I had a mortgage to repay and a family to look after. This also meant that I did not take any more Factor VIII after marriage.

## ANONYMOUS

- 2.11. I have only ever received Factor VIII blood products for my haemophilia condition. Otherwise, I have never taken drugs intravenously and I do not have any tattoos.
- 2.12. When I was given Factor VIII, I was aware at the time that it was extracted from human blood. However I was never informed of any risks associated with Factor VIII use nor was my brother informed as the attending adult. I was just pleased that I had access to it and that it would allow me to heal and play football.

### Discovery of the Hepatitis C virus

- 2.13. It was in the late 1980s (again I am unsure of the exact year) that I received a letter from Lewisham Hospital asking me to come in for a blood test to see if I was infected with HIV. I am unsure what prompted this letter.
- 2.14. When I received the letter from Lewisham Hospital asking me to attend for testing for HIV, my knees buckled. It knocked me for ten. I don't know how you can react to things like this. At the time, Freddy Mercury was going through the HIV infection and there was nothing left of him at the end.
- 2.15. I do not have a copy of this letter and must have thrown it away. In my mind, this was the best thing to do with something that could give you a heart attack.
- 2.16. Following receipt of the hospital letter, I attended the hospital to have a blood test and was told that I would be tested for HIV.
- 2.17. I found out my results a couple of weeks later. I experienced a huge sense of relief when I was informed that I was HIV negative but then I was told that I had Hepatitis C.
- 2.18. I am not sure of the exact circumstances in which I was informed of my diagnosis; however I believe that I was told orally by a doctor rather than via a letter. I didn't know what Hepatitis C was. All they told me was that it was a relatively new disease and that hospitals were not therefore screening for it.
- 2.19. I was not given any information by the hospital to help understand and manage the infection. However they did tell me that I could not pass Hepatitis C onto my family.
- 2.20. I received no additional advice from my GP on how to manage the infection.

## ANONYMOUS

- 2.21. The only advice I was given was to reduce alcohol consumption - this was one of the main concerns of the hospital. Otherwise I was not given any other advice about making lifestyle changes.
- 2.22. After making the Hepatitis C discovery, I have not set foot in Lewisham Hospital. I transferred to St Thomas' Hospital and they gave me more information, including that Factor VIII is made from white blood cells extracted from gerbils.

### Other Infections

3. I was infected with Hepatitis C only.

### Consent

4. I consented to the blood test for HIV.
  - 4.1. I did not consent to the blood test for Hepatitis C as I was not informed about it prior to the test. The excuse that I was given by the hospital for the lack of information was that it was a new disease that the hospital did not know much about it.
  - 4.2. I consented to the treatment of Hepatitis C in 2018.

### Impact

#### Mental and physical effects of being infected

5. I was gutted to learn of my Hepatitis C infection. I didn't cry. I just asked how I could get rid of it and was told "we don't know". Doctors told me it was a new disease. I was told that I had got it via infected human blood and that blood could have come from any country.
  - 5.1. Their attitude was that as this was a new disease they were not to blame. This was a punch in the mouth but what could I do? If it was a new disease and there was no cure then what could I do? As horrible as it was and even though it gave me mental stress, I did not cry.
  - 5.2. I felt like I couldn't do anything about my condition and spent lots of time worrying about it. Every night I went to bed and wished I was dead. I thought "what was the point of living"? You can't tell anyone, no one is going to help you, all you can do is keep it bottled up and hide it from your wife and children. The horrifying thought is you can't tell anyone because nothing is going to be done.
  - 5.3. I wanted to end it but I don't think I am man enough to commit suicide. I don't know how to put it in words.

## ANONYMOUS

- 5.4. Despite my Hepatitis C diagnosis, I forced myself to grin and bear it and just get on with it. I was mentally drained but felt that I had to persevere. During the hard times in the 80s I would have a beer and things would then be okay. I am the head of the family and so there was no one for me to complain to. I had to carry on. Things may have been different if I had my mother and father here. I don't know how I would have reacted then.

### Further medical complications

- 5.5. Hepatitis C has led to liver stiffness. I have an FAS score of 10 as of 1 May 2018. I know this because it is recorded in a clinical letter shown to the Inquiry. To put this into context, I think that if the score goes over 14 then this is the beginning of cirrhosis of the liver; however I am not 100 percent sure.
- 5.6. I also have elevated blood pressure due to the additional stress and worry resulting from my Hepatitis C diagnosis. I take Lisinopril and Indapamide every day to treat this.
- 5.7. I was informed by my dentist that I had gum problems but I am unsure whether this is linked to my Hepatitis C. My gums had to be cleaned from behind the teeth and I was warned that I would have lost teeth if action was not taken. This is why I have dentures on my top and bottom teeth.

### Treatment for Hepatitis C

- 5.8. When I was first diagnosed with Hepatitis C I was offered treatment. However I refused any treatment until I was 100 percent sure in my mind that it would be successful.
- 5.9. The reason for this is due to the horrors experienced by my brother during his treatment for Hepatitis C. My brother had injections put into his belly in the 90s to treat his infection. These caused him to have nervous attacks and experience severe anxiety. He would run out of his house into the road in a panic and the anxiety prevented him from breathing properly. After seeing this I thought I am not taking that.
- 5.10. I continued to refuse treatment until I was given a definitive answer that there was a 100 percent chance of a cure for Hepatitis C. It took 40 years for such an answer to materialise.
- 5.11. In 2018, I commenced a 12 week course of treatment at St Thomas' Hospital. I would take oral medication (2 tablets, 1 in the morning and then 1 at night) and received regular blood tests to check the level of

## ANONYMOUS

virus in my blood. The treatment was convenient as I simply had to go to the pharmacy to pick up my medication.

- 5.12. I was under the care of Graham Thompson and Jenna Stanley. I was informed that the medication was new and expensive and that 100 percent of people who took it were eventually cured. This was good enough for me. Jenna gave what I describe as "beautiful information".
- 5.13. I had a grin on my face every time I went to see Jenna to get my blood results as my viral load kept reducing.
- 5.14. After I had finished my course of oral medication I had to wait 12 weeks before my final blood test to allow the medication to do its work. I went away to India for 5 weeks during this period as I needed a break.
- 5.15. I was found to have an undetectable viral load when I was finally tested. This was confirmed via a clinical letter dated 01.05.18 shown to the Inquiry. I was informed that I would not get Hepatitis C again unless I received infected blood in future.

### Mental and physical effects of treatment

- 5.16. During the course of my treatment for Hepatitis C I experienced tongue swelling and my tongue went blue with black spots. My face became sunken and skinny, I lost weight and I had spots on my body. My skin also darkened.
- 5.17. I also experienced a significantly reduced appetite. I would come back from work at around half six and my wife would have dinner ready. Normally I would have 3 or 4 chapatis. When I was taking my Hepatitis C medication I would only have 1 chapati. I might have 1 slice of bread with soup and would have to force myself to have another slice.
- 5.18. I was told that I may get headaches as a side-effect of the Hepatitis C medication I took. I had headaches but nothing that would make me want to hit the wall to get the headache out of my system. I did experience dizziness and would often seem drunk to my wife.
- 5.19. I would get angry and agitated quite easily when I was on my medication. This did not happen too much but I was certainly not my usual self.
- 5.20. I developed a mild form of depression. During my treatment I was thinking am I going to lose it like my brother who suffered as a result of his own treatment for Hepatitis C or am I going to be cured.

## ANONYMOUS

- 5.21. I have also developed an extremely itchy rash on my upper body which was not there before I took medication for my infection. I am unsure whether the two are linked or not.

### Other medical and/or dental care

- 5.22. All my medical professionals including Dentists were aware that I had Hepatitis C. I did not experience any negative treatment as a result of my infected status.

### Impact on my private, family and social life

- 5.23. My wife burst into tears when I told her that I was Hepatitis C positive, which was shortly after I had been informed myself. She asked me "what do we do" and I responded "nothing, there is no cure".
- 5.24. I informed my two sons when they were 15-18 that I was Hepatitis C positive. My children have grown up with my condition and it was not really breaking news. My sons knew that I was a haemophiliac and that Hepatitis C was something I had and that there was no cure. My children did not discuss the infection with other people.
- 5.25. In my view there is no point in moping about it. There is no one to listen to that.
- 5.26. However my wife can't forget what has happened and her emotions boil over. I don't do this. I keep it bottled up. Perhaps this is wrong and I should share my emotions but what are my family going to do? They do say if you talk about things it makes it better. However the only person I could ever talk to is my wife or my two sons and what I tell them is not the whole story.
- 5.27. My family could sense that they were not being told everything and could see the impact.
- 5.28. My condition has not impacted on my education and I was able to finish a GRO-B course in 1979 in bricklaying, which I passed with flying colours.

### Education/work/financial effects

- 5.29. My condition has not significantly impacted on my education. I completed my education and I have learnt everything I wanted to outside of school, including taking a GRO-B bricklaying course in 1979, which I passed with flying colours and undertaking my training to become a driving instructor.

## ANONYMOUS

- 5.30. There was also no impact on my work or financial situation because I have a family to look after and just have to get on with it.

### Treatment/Care/Support

6. I do not recall ever being offered counselling for my condition.
- 6.1. My view is that life goes on and you just have to get on with it. The only person I discussed my diagnosis with was my wife as she is my life and soul.
- 6.2. I do not really have any friends outside of my family and I do not tell people about my Hepatitis C infection. As I was told Hepatitis C cannot be passed on it was my view that there is no point in telling people.
- 6.3. A couple of my students know that I have Hepatitis C. One student has a friend with HIV who appeared on TV when there was a big thing going on about the HIV/Hepatitis C infection amongst haemophiliacs. It was during that conversation that my student and I discussed my infection briefly.
- 6.4. I have not discussed my Hepatitis C infection with my relatives in India as they wouldn't know what it is. I went to see a doctor in India around 5-8 years ago and they didn't even know what haemophilia was.
- 6.5. Although I have detailed the adverse impact of my treatment, the end result was no Hepatitis C after 40 years with the disease. It's an itch I can scratch now.

### Financial Assistance

7. At some point in the 1990s I received a letter from the government informing me that I would be receiving a one-off payment. This payment was to be the end of it. The government were effectively saying "here you go, now shut your mouth". I am unsure of when exactly I received this letter and I have not kept a copy of it.
- 7.1. As a result of the letter I was given £20-25,000 from the government. I do not recall having to sign anything before receiving the payment.
- 7.2. In 2016-2017 the Skipton Trust ('Skipton') got into contact with me via a letter. They informed me that they would be fighting the cause for haemophiliacs and that I would get additional money to try and keep me going.
- 7.3. In order to claim, I had to return a form which my sons completed for me. The nurse, Jenna, who was treating me at the hospital also



# ANONYMOUS

completed a form following my doctor's advice. This explained about my medication and symptoms and was sent to Skipton.

- 7.4. I subsequently received a letter stating that as of 27 August 2018 I will be paid £362 per month (as my household income was assessed to be in the bracket of £7,601-15,200). I also received a back payment of £1448 to cover the period since April 2018. I have been informed that Skipton payments are made tax free.
- 7.5. It took a course of letters back and forth for a period of 1-2 years before I received payment from Skipton.
- 7.6. In terms of my views on the financial support made available I can only say thank you to Skipton because I never contacted them, they made contact with me. I didn't even know about Skipton before I received their letters. Any money that I receive is a bonus.
- 7.7. I believe that there is not a lot that can be done to get better financial support for infected people. I am not going to be able to go up to the Queen and ask for something to be done or the Prime Minister. What are they going to do? All we have been given are false bureaucratic promises of a better tomorrow.

## Other Issues

8. There is nothing else that I really wish to talk about. However I will say one thing - it is often the mind-set that keeps you going. I am a fighter and describe myself as "proper old school". I have always "worked hard and starved". If my legs are broken, only then will I not go into work. I have got a family to support and so I have to work. And that spirit remains in my blood.

## **Statement of Truth**

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

Signed GRO-B

Dated 3/12/18