

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3247001

Exhibits: 0

Dated: September 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 the GRO-B 1959 and I live at GRO-B, Norfolk GRO-B with my wife, GRO-B. We do not have any children and I work as a long distance lorry driver. I have been employed by the company I work for for over 20 years.

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

### Section 2. How Affected

3. I was diagnosed with severe Haemophilia B when I was 3 or 4 months old at the time I received my first inoculations.

## ANONYMOUS

4. In the early days I was treated with blood transfusions and plasma. I started receiving Factor 9 when it first became available; I was about 15 or 16 years old and would inject myself every other day. I used Factor 9 until February 2015 when I had a liver transplant. As a result of the transplant I no longer have Haemophilia.
5. I was treated at Norfolk and Norwich University Hospital Haemophilia Centre by Dr Black and Dr Hamish Lyal.
6. As far as I am aware my parents were never given any information or advice before hand about the risk of being exposed to infection from blood products.
7. As a result of being treated with blood products I have been infected with Hepatitis B (HBV) and Hepatitis C (HCV).
8. In July 1996 I was due to have an ankle fusion operation and blood samples had been taken. During the pre-op check, about a week before the operation Dr Fellows told me that the samples had revealed that I had HCV, it was a massive shock. I was also told I had cirrhosis of the liver and that I had cleared HBV. I do not know when I was infected with HCV or HBV.
9. I was not told a lot about the infection from memory. I believe I was told of the symptoms I could expect. I had not been unwell up until that point so I was not aware I had any infection, I was more concerned about the ankle surgery.
10. I do not believe I was given adequate information to help me understand and manage the infection, we were not told a lot, we did most of our own research into the condition rather than wait to be told by the hospital. We should have been told more and sooner.

11. I was told of the diagnosis in a very matter of fact manner and I felt it was being swept up under the carpet in a way. Also I was not given any information about the risk of others being infected

### **Section 3. Other Infections**

12. I am not aware that I have received any other infections as a result of being infected with blood products; although I have been told I am at risk of CJD and there are warnings of this written over my hospital records which I see when I attend appointments.

### **Section 4. Consent**

13. As I had Haemophilia blood samples were often taken but I have no idea if these samples were tested for infections.
14. However, I am certain the hospital must have known I was infected before they told me so I was not given adequate or full information about the reason for the blood tests.
15. I do not know if I have been tested for research purposes, however, the chances are they could have tested my blood for research but I have definitely never been told.

### **Section 5. Impact**

16. The diagnosis of HCV was a massive shock to me and [GRO-B]; mentally it really rocks your world. Even though as a Haemophiliac you get used to hearing things from the hospital it did hit me hard but I took the diagnosis better than [GRO-B].

## ANONYMOUS

17. Physically I suffered from sickness, fatigue and stomach pains. I had good days and bad days but I had more bad than good days.
18. As mentioned I had cirrhosis of the liver as well as portal hypertension which would cause bleeds from my stomach. I had 8 or 9 attacks where I vomited blood and blood clots randomly. I was at a friend's house when the first attack happened, it was very concerning.
19. I had an endoscopy and my stomach vessels were cauterised. Apparently the hypertension was a sign of liver failure.
20. In November 2014 I was diagnosed with liver cancer, I had two lesions of cancer on my liver and I was given 12 months to live. A liver transplant was recommended but I had to get the correct match to have the transplant. In the meantime the hospital proposed radiotherapy but that might have made me too ill for surgery so they withheld treatment for as long as possible. Fortunately I was lucky and I was able to have the transplant on the 25<sup>th</sup> February 2015.
21. Unfortunately however at the moment I have a blood clot in an artery which is causing my liver to fail and so I will have to have another transplant. I do not know the time frame but when I get to a certain point I will be placed on an emergency transplant list and I will have to wait for the appropriate match.
22. Also due to the ant rejection drugs I take I have severe kidney disease.
23. In 2007 I had a six month course of Interferon with Riberviron for my HCV; it was the worst six months of my life. I lost weight, I felt sick, I had headaches, I had fatigue, I had every side effect possible. I would look in the mirror in the morning and would not recognise myself. It was absolutely hell it was the worse thing I have had

## ANONYMOUS

24. Half way through the course the side effects were so bad that the hospital were considering taking me off the course but the treatment was working, it was destroying the hepatitis virus so they recommended I stay on it.
25. The course of treatment was really tough and I felt I was heading towards depression. However, I like to think I am quite a strong character but it was a really very difficult time.
26. As I had a mortgage to pay I only had 3 days off work in those six months, it was really tough.
27. As a result of haemophilia my elbow and ankle joints are fused joints, my joints are generally bad. However due to HCV I had to wait a little longer for the fusion operations I had as I understand the surgical instruments were destroyed after surgery.
28. I have not told many people I have been infected with HCV just a few close friends and my immediate family, my mother and [GRO-B]. My father has died.
29. When I was diagnosed [GRO-B] and I had not been together for very long and we were due to get married and as a result of the diagnosis we decided to move our wedding forward to before my ankle fusion surgery.
30. My diagnosis has had a heavy impact on my mother and [GRO-B]. My mother blames herself as she gave birth to a Haemophiliac son. She has not had any counselling.
31. Following my diagnosis [GRO-B] nearly had a breakdown and had to be treated by her GP for some time. She was prescribed medication. She is still not 100% and has good days and bad days. She was also tested for HCV but fortunately the test was negative.

32. I am concerned about the second transplant I am due to have I am always thinking about it, it is always in the back of my mind. I understand the second transplant will be more dangerous than the first one and the liver is more likely to be rejected due to infection.

33. I have not suffered from any stigma as very few people know about my infection and those that do are very sensible and understanding.

34. My employer has also been quite accommodating. There are parts of the job I cannot do as I get fatigued and become tired very easily. But my job is molded round me but I cannot work long hours so I miss out on salary.

35. When I had the transplant I had 6 months off work with no pay. I received £88 a week statutory sick pay which I could not survive on and as a result we lived on our savings which have been spent. Family and friends also helped and without their support we might have lost our home.

#### **Section 6. Treatment/Care/Support**

36. I cannot recall that I have faced difficulties or obstacles in obtaining treatment as a result of being infected with HCV. However I have never been offered any counselling or psychological support or any other support.

#### **Section 7. Financial Assistance**

37. I was told financial assistance was available from the Haemophilia Society shortly after I was diagnosed with HCV and have received the 1<sup>st</sup> and 2<sup>nd</sup> stage payments from the Skipton Fund which is now the EIBSS.

38. I had someone round to see us to assist in the application process for the financial assistance, as far I recall it was not straight forward.

**Section 8. Other Issues**

39. I want to know why this happened and I want the truth about what happened.

**Section 9. Anonymity, disclosure and redaction**

40. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

41. I do not want to be called to give oral evidence to the Inquiry.

**Statement of Truth**

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

Signed.....

GRO-B

GRO-B

Dated ..... 10.10.19 ..... 2019