

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN 1340001

Exhibits: 0

Dated: November 2018

29

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 GRO-B and I live at GRO-B where I live with my family: my wife, son GRO-B and daughter GRO-B.

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 mild haemophilia A. As a result there were two occasions, as far as I am aware when I was treated with Factor VIII: the first one being when I had my GRO-B GRO-B and the second one when the joint of my GRO-B GRO-B I was treated by GRO-B.

4. As I was GRO-B years old when I received my first Factor VIII treatment in GRO-B my parents had to consent to it. As far as I am aware none of us were given any

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information as to the potential risks before any of my treatment. I do not think that any patients were told about the risks at the time.

5. I was infected with Hepatitis C (HCV) as a result of the treatments referred to above.
6. **GRO-B** I went to work in **GRO-B** when I was working for **GRO-B** I applied for life insurance **GRO-B** and was turned down. The routine medical check for the insurance policy showed I was infected with the HCV virus. I was confirmed of my condition on the **GRO-B** **GRO-B** I was very shocked and did not know how this could be also by that stage I was very ill, my liver had been damaged.
7. Following the diagnosis, **GRO-B** in order to seek more information about my condition, thus I had another check-up in the **GRO-B** **GRO-B** which confirmed that I was infected by the Hepatitis C Virus (HCV) and that my liver function was already very poor.
8. As advised by **GRO-B** my two treatments with Factor VIII were the only occasions when I could have been infected with HCV.
9. I was not been given a lot of information about HCV and what it would mean for me. I do believe that I could be given more information. I think that HCV was a fairly rare disease and the tests **GRO-B** could only tell you whether you are infected; not in-depth details about the infection. Thus, all I knew was the information from my medical reports.
10. As I had regular medical check-ups in the UK prior to being diagnosed I have reason to believe that the doctors in the UK knew about my infection in the **GRO-B** closer to the date when I was infected, however I was never informed about it.
11. I truly believe that I should have been informed about the fact that I was infected with HCV a lot earlier and without me needing to seek the information on my own account.

**Section 3. Other Infections**

12. I believe that I have been exposed to the risk of [GRO-B] as well via the factor VIII infected blood treatment.

**Section 4. Consent**

13. I definitely believe I was treated or tested without my knowledge, or without my consent, or without being given adequate or full information or for the purposes of research. I recall in [GRO-B] I received a letter from the [GRO-B] stating that I might have been infected with HIV and that I should have blood tests done to check it. I was extremely worried and shocked, due to the severity of the illness. Therefore, I had a number of blood samples taken in the late 1980s to test me for HIV, but luckily they were negative.

14. I was also approached by a Patient Liaison Officer at that time, [GRO-B] at the [GRO-B] and I was asked to donate some blood on a voluntary basis, as I was a mild haemophiliac, thus the doctors were interested in performing tests on my blood to explore the illness. However, I have never heard back from them, so I believe that they have secretly tested me for hepatitis at that time, but they have not informed me about it.

15. I also applied for a copy of my medical report from the National Haemophilia Database which is dated the 5<sup>th</sup> May 2018. The report appears to show that I received two more treatments from [GRO-B] [GRO-B] However, I do not remember the reason for those treatments.

16. Further, the report shows I was also tested for the [GRO-B] [GRO-B] with risk of exposure, which I had not been informed about, either the test or the result.

17. A summary of the report appears in the schedule at the end of this statement.



**Section 5. Impact of the Infection**

18. In **GRO-B** during a review at the **GRO-B** following my return from **GRO-B** I was advised to have the interferon treatment. However, I did not receive comprehensive information, as the doctors did not tell me about all the consequences of the treatment, especially those which would become apparent in later life. All I was told was that I should be treated by using interferon injections, as it might prolong my life-expectancy, which is shortened by the virus. Also my liver function was already poor and also other functions were out of the range.
19. I was advised to take the interferon treatment by the **GRO-B** **GRO-B** but I could not have it done here, as I had to work in **GRO-B**. On my return to **GRO-B** I received the treatment privately, as it was not available to me there. I had to pay for the treatment from my own finances, which amounted to around **GRO-B**. It is clear that, I was infected with HCV in the **GRO-B** however I was treated in **GRO-B** the treatment method was advised by the doctors in the **GRO-B** and confirmed by a doctor in **GRO-B**.
20. Following my diagnosis, I had the interferon treatment for about 12 months, which cleared the HCV, however my doctor advised me to continue the treatment for another 6 months to prevent it from recurring. The whole treatment took 18 months. However, I have been informed that HCV can potentially return at any time.
21. I was very nervous of having the virus itself, as it is a serious illness affecting my everyday life, both back then and now. At the time, I was working in **GRO-B** **GRO-B** without the ability to get life insurance coverage, because of the HCV. I found it very stressful, as I already had my family to provide for.
22. I was also afraid of the treatment, because of the reported side-effects, including anxiety, weight loss, itchy skin, hair loss, memory loss and excessive tiredness, as well as the possibility of dying due to the infection causing bleeding in my liver.
23. I struggle with excessive tiredness, lack of concentration and memory loss to this day. I often suffer from a foggy memory and confusion. This affects my ability to work full-time.

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24. The infection has also affected my personal life. It has caused me a lot of stress, as I did not want to inform anybody about it, including my employer. The only people who know about it are my doctors and my family. I was also worried about the possibility of transmitting the virus to my family, which luckily has not happened.
25. My condition has also had an impact on my finances, the obvious one being the payment of the GRO-B for the interferon treatment in GRO-B. I have also paid for my own insurance, rather than using one offered by the company I have worked for, as I did not want them to find out about my infection, due to the stigma attached to it.
26. The virus has also had a significant negative effect on my career. I believe that due to my decreased performance caused by the symptoms, I have missed out on various opportunities, such as promotions, which has also affected me financially. I also had to spend a lot more time on the various activities at work, as a result of my memory problems and inability to concentrate.
27. I started my career in the GRO-B however, I was made GRO-B due to constantly being tired and forgetting things. I then started a another job; however I was made GRO-B again, in GRO-B. This also had an effect on my finances, as I was not able to earn money anymore and affected my pension.
28. My HCV has been resolved by the interferon treatment; however, I was informed that there is still a potential of it returning. Therefore, I have to have regular medical check-ups, which is very stressful for me and my family.
29. I have always enjoyed GRO-B however I am not able to do it anymore because I get tired easily and I need regular breaks to rest. This is the same as with many other activities, which affects not only my enjoyment, but also the ability to do it.

### Section 6. Treatment/Care/Support

30. Other than the fact that I could not proceed with the interferon treatment in GRO-B due to the need to work GRO-B and thus needing to pay for my treatment there out of my own finances, I have not had any particular problems with obtaining

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the treatment. The treatment was easily available, as I have contacted a doctor privately and paid for it. Moreover, considering that there were not many people in the area who suffered from HCV, there was a sufficient supply of the treatment.

31. I was never offered any counselling or psychological support. I was never contacted by the health service in the UK, nor by the Haemophilia Society regarding my condition. For the last 20 years, from the time I was infected I have not been given any information.

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

32. I did not know about any Trusts or Funds until the Christmas 2017. I was watching the BBC news, when I saw [GRO-B] I contacted him and he invited me to join the support group. There was a gathering in [GRO-B] and that is where I found out about the various Trusts and Funds which had been put into place.

33. As a result of my application I was offered the Stage 1 payments from the England Infected Blood Support Scheme. I was paid the total of [GRO-B] [GRO-B] and I receive [GRO-B]

34. The only condition which I needed to meet was to be able to provide my records from the hospital confirming my condition. Therefore, the application process was fairly easy for me as I was able to provide all the relevant evidence. However, I am aware that it was a lot harder for other people who are missing some evidence.

35. In a letter from the England Infected Blood Support Scheme, dated [GRO-B] I was informed that I might also be eligible for the HCV Stage 2 or Special Category Mechanism payments, which are complimentary to the Stage 1 payments. I am intending to apply for them; however they are harder to be accepted for as there is more information needed.

36. I am planning to travel to [GRO-B] in order to obtain further medical records and I have also recently contacted the [GRO-B] to access more information from them. However, I was told that they were destroyed, which I think is unacceptable, as this is likely to affect my application for the Special Category Mechanism payments.



**Anonymity, disclosure and redaction**

37. I confirm that I do wish to have anonymity and that I understand this s  
published and disclosed as part of the Inquiry

38. I do not wish to be called to give oral evidence.

**Statement of Truth**

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

Signed

GRO-B

GRO-B

Dated

29

November 2018

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## MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

GRO-B Diagnosed – mild haemophilia A at GRO-B  
 GRO-B Clinical Notes – bleeding gums  
 GRO-B Letter GRO-B mild haemophilia 'A' (factor VIII level 20%) admitted with a haemarthrosis of left knee. Treated with bed rest and analgesia, factor VIII cover and physiotherapy. GRO-B  
 GRO-B Letter from GRO-B confirming Hepatitis C was contracted from factor VIII concentrates received. Interferon advised.  
 GRO-B Letter from GRO-B confirming liver function tests normal and tested negative for Hepatitis C. Advises caution optimism as up to 50% of patients relapse.

GRO-B Report from the National Haemophilia Database:

### Treatment Record

Treatment Yr

Centre

Product

GRO-B

GRO-B

FVIII (BPL)  
 Cryoprecipitate  
 FVIII (BPL)  
 Cryoprecipitate

### Hepatitis C data

Information Submitted by

Result of Anti Body Test

Result

GRO-B

Pos

Pos

### vCJD data

Centre

At Risk

Patient Notified

Assessed Date

GRO-B

Yes

Unknown

GRO-B

### HIV data

Centre

Sample date

Result

Date Form

Completed

GRO-B

GRO-B

GRO-B