

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1195001

Exhibits: 0

Dated: November 2018

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 and I live at GRO-B with my wife, GRO-B I retired GRO-B having taken early retirement on health grounds. I worked for GRO-B GRO-B GRO-B I have GRO-B grown up children and GRO-B grandchildren.

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

Section 2. How infected

3. I have Haemophilia A and my condition is severe. I have been given blood products many times, although severe I do not get spontaneous bleeds very often, I did tend to get joint bleeds quite regularly. When I was younger I used to do the same things as other young people did, which caused me to need to go to the hospital quite often. I was in the hospital over 100 times before I turned 10.

## ANONYMOUS

4. Overall, my need to have the Factor VIII treatment was quite unpredictable, as sometimes I did not need any treatment for 10 months, and sometimes I needed it a few times per week.
5. The products would have been: BPL, Cutter and Armour.
6. I was registered at a number of different hospitals: [GRO-B] Hospital from when I was born [GRO-B] till [GRO-B] [GRO-B] to [GRO-B] at [GRO-B] Hospital for day to day treatment as I worked there; [GRO-B] to [GRO-B] Hospital and [GRO-B] to date returned to [GRO-B] Hospital. I was most likely infected at [GRO-B] Hospital in the [GRO-B] and [GRO-B]. I am not sure when exactly, as I had regular treatments with blood products.
7. At [GRO-B] I was treated by Prof. [GRO-B], followed by Prof. Savidge, then Dr [GRO-B] at [GRO-B] I was treated by Dr [GRO-B] and at [GRO-B] by Dr [GRO-B].
8. I was never given any information as to the risk of an infection caused by the blood products. [GRO-B] therefore it could not be something widely known about. I assume that it might have been known amongst the Haemophilia professionals.
9. I found out that I was Hepatitis B and HIV positive in [GRO-B]. There was a general concern about HIV infections. At that time is also when many haemophiliacs were tested.
10. I had a few blood tests at the [GRO-B] Hospital, as requested and I was asked to go back to see Dr Savidge, in order to get my test results. I did not know him very well at the time and this was probably only the second time when I saw him. He put his feet on his desk, lit a cigarette and told me that I was HIV positive. This was the first HIV test that was performed that I know of.

# ANONYMOUS

11. I was not given any treatment at the time.

12. I am not aware of being tested for Hepatitis B or C at the time. I only found out about my Hepatitis C infection once I changed from [GRO-B] to [GRO-B] Hospital in [GRO-B]. I am not sure whether anybody knew of my Hepatitis infections prior to that.

13. I was provided with some information about Hepatitis; however, at the time there was no specific treatment for Hepatitis C Virus (HCV). Therefore, it is hard to tell whether I should be given more in-depth information earlier, because I am not sure about how much was known about the virus and the treatment.

14. In the late 1990's there were some evidence showing that the Interferon treatment might work, but nobody knew the exact doses. I was then referred to Dr [GRO-B] at St, George's, who managed to get me on the clinical trials; however, it did not work. The viral infection left me with severe liver damage.

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

15. To my knowledge, there were no other infections that I contracted in the process of being treated with blood products. However, I did receive a letter stating that I might be at risk of CJD, but I did not have any tests for it.

16. I do not wish to take it further, as I do not wish to know if I have contracted CJD. If I do have it, there is nothing that I can do about it, therefore I would much rather not know about it so that I do not have to deal with the stress related to the knowledge.

### **Section 4. Consent**

17. I have no knowledge either way yet as to whether I have been treated or tested without my knowledge; or without my consent or without being given adequate or full information, or for the purpose of research.

**Section 5. Impact**

18. In the early days, back in GRO-B there was no specific effect. I had some health problems relating to HIV; however, I managed to live with it as there was no treatment available at the time.
19. However, once I found out about all the viruses which I have contracted in the late 90s, I started an actual treatment at GRO-B
20. I have suffered a lot of discomfort caused by the drugs given to me. I was originally put on AZT with another drug; however, my CD4 count was quite low, so they put me on stronger drugs (protease inhibitors), which were horrendous. They made me very ill for the 3 months or so that I took them, however, they did work.
21. I still feel the side-effects of the treatments given to me of Interferon and ribavirin for Hepatitis C. I do not feel like the same person that I used to be. There are good and bad points to their side-effects. The good point is that I never got a cold, as they protected me from viral infections. However, there was a point when I lost a lot of weight over a short period of time, due to the medication given to me. Once I finished taking the medication I gained a lot of weight very suddenly. It is extremely difficult to lose the weight, which I was informed about at GRO-B Hospital.
22. I did always try to keep my infections private. I never told any of my co-workers about it, not even my children know about HIV but they do about Hepatitis C. This is because of the stigma attached to those viruses, both at the time and now. They knew that I had some treatments for Hepatitis C.
23. My infections have not affected my work for a very long time. However, the problem with HCV is that it is a very insidious disease, as you do not get any symptoms until the cumulative damage is done.

## ANONYMOUS

24. Whilst it did not affect my work, per se, it did affect my retirement and my pension, which I believe is partially due to haemophilia and partially to the infections I contracted in the process of treatment.
25. Before I retired, I was very active in my professional life, as not only was I working in my original job, I was proposed to work as a [GRO-B] within the [GRO-B] which would have required me to travel a lot. This post subsequently was never filled.
26. However, this has coincided with a bleed in my knee. I visited [GRO-B] Hospital with a hope to get a treatment for it. The doctor at the hospital suggested to me to have early retirement, however I did not want to do it, as I genuinely enjoyed my job.
27. I then went to my GP, in order to get some pain killers. I was also advised to take 3 months off work to recover fully, which triggered a process of checking whether I was fit for the job. Therefore, I was asked to have a medical.
28. The medical was done by a doctor who had done a haematology job, who said that that at that point I have worked for long enough, and that I should take early retirement. I believe that retiring should be a happy process, which a person should be able to prepare for, instead it happened so suddenly for me, I was not able to prepare for it (including financial preparation) and I was shocked. I was quite upset that I had to retire at 56 without being given much choice about it, as I found my job very interesting; it gave me great enjoyment, I loved it, therefore I did not wish to end my career at the time.
29. Early retirement triggered by my health problems also affected me financially. I retired 10 years earlier than I intended to, which resulted in me losing out on pension. I expected to retire around 5 years ago, which would result me in getting my NHS pension top up.

## ANONYMOUS

30. My infections have also had a negative impact on my wife. Thankfully, my wife did not contract any of the infections from me, however my infections did have a toll on her, as she was with me, supporting me all the way through.
31. In terms of my Hepatitis B, it is a relatively small problem compared to my other health issues. However, it is another strain on my liver.
32. When it comes to having a life or health insurance, I had to forget about it. It might be possible to get it; however, I would have to pay a lot more for it.
33. I saw many people on the haemophilia websites complaining about that either they were not able to get insurance at all, or it was extremely high, but generally they would only cover everything other than the illnesses they already had.
34. When I travel, I rely on the EU Health Insurance Card, but overall, I do not have a separate travel insurance card, because of how expensive it is for me and the fact that it does not cover the health problems I already have. This is quite problematic because [GRO-B] live in [GRO-B] so I travel there quite regularly. Whereas, whenever I go on a holiday outside the EU, I have to rely on insurance, which does not cover my illnesses.

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

35. Considering that I was working [GRO-B] I had no problem accessing the treatment. I was often treated at work and was able to carry on with my work as normal.
36. I have interviews with a psychologist once a year at the Haemophilia Centre check up to make sure that I am fine, these have happened for around last 3 or 4 years.
37. I am also a lot better now, with my current treatment. Once I returned to [GRO-B] Hospital, I was seen by a virologist, who tested me and prescribed the Interferon ribavirin treatment, which thankfully worked. It was the same treatment, as the one I was given before, but this time they knew the right dosage. However,

# ANONYMOUS

Interferon is a horrible drug, which is not given to people with psychological problems, because of its side-effects. It causes depression and mood swings even in normal people. But thankfully I tolerated it quite well. The damage to my liver is still present.

## Section 7. Financial Assistance

38. I believe that I was informed about the financial assistance available to me by a doctor at the GRO-B Hospital. I filled in the form and the doctors countersigned it then posted it. It was some time in the 90s, however, I am not sure when exactly and I believe that it was the McFarlane Trust.

39. I received the initial payment of £60,000, and I was made sign a declaration that I would not take any further legal action.

40. I did sign the declaration; however, I did not get any legal advice on it, as at the time it was not as widely available, as it is now.

41. I have also received another payment from the Skipton Fund for my HCV. That was around the year 2000 and I was awarded with around £16,000.

42. I have also received non-discretionary monthly payments for co-infection with HIV and stage 2 HCV, both from the Skipton Fund and MTF, which depend on what a person is infected with and the degree of damage done by HCV. My entitlement to the discretionary fees is means tested, which includes my state and NHS pensions and my wife's pension. I do not think that it is fair that they are taking my wife's pension into consideration.

43. I have also just started receiving discretionary sum of £64 per month as the rules have changed.

ANONYMOUS

44. Also until recently I have been above the income threshold for discretionary payments.

45. Overall, when it comes to the application process, I think it was straight forward and I had no trouble with it though some people on the phone could be abrupt, but Neil Bateman was brilliant.

**Section 8. Other Issues**

46. My main concern is the potential amount of time that this enquiry will take. I am GRO-B GRO-B and have some health issues. We have already waited for a very long time for this to happen.

**Anonymity, disclosure and redaction**

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

48. 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        23<sup>rd</sup> November 2018