

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1081001

Exhibits: WITN1081002-9

Dated: August 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 and I was born on GRO-B.  
I live at GRO-B.
2. I was infected with Hepatitis C and HIV as a result of receiving contaminated blood products.
3. **This witness statement has been prepared without the benefit of access to my full medical records.**

#### Section 2. How Infected

4. When I was a child my parents took me to the hospital because my whole arms and legs were covered in bruises. The hospital staff accused my parents of child abuse. Subsequently I was diagnosed with severe Haemophilia A.

## ANONYMOUS

I received Cryoprecipitate and attended a school for children with disabilities until the age of 7.

5. I attended Newcastle-under-Lyme Hospital and I was under the care of Dr Ibbotson.
6. I attended Queen Elizabeth's Birmingham Hospital and I was under the care of Dr Wilde.
7. I was later treated with Factor VIII concentrate. The first time I received Factor VIII was at the hospital prior to receiving home treatment which I was trained how to administer. I didn't have to go to hospital all the time anymore which was excellent.
8. My mum and I were told it was a fantastic drug because it would enable me to live my life more freely. I recall that the nurses asked my mum if she wanted to send me to Treloar's School but she decided against it and sent me to a normal high school.
9. At age 13 I found out that I had been infected with HIV. We saw the TV adverts in relation to the AIDS virus and my mum took me to the doctor who confirmed that I was infected. I fainted. It was known as the "gay and drug addict's disease". I refer to **Exhibit WITN1081002** which is a letter dated 30 October 1985 from Dr Ibbotson which states *"Unfortunately, although expectedly GRO-B has antibodies to the HTLV III virus. This does not mean that he has AIDS or that he will develop AIDS. I had a long discussion with GRO-B mother and GRO-B and they understand the implications."* I recall the discussion was brief and that we were not provided with adequate information. The doctor's prognosis was that I had 2 years left to live. This news completely destroyed my parents.
10. Aged 14 I was called into the doctor's office again and he revealed that I had also been infected with Hepatitis C which was another shock to me and my parents. I refer to **Exhibit WITN1081003** which is a letter dated 20 October

## ANONYMOUS

1992 from Dr Ibbotson confirming that *"results of investigations reveal that he has Hepatitis C antibodies which indicate that in the past he has been exposed to Hepatitis C and is now a carrier"*. A further letter dated 19 September 2007 from Dr Hay presented as **Exhibit WITN1081004** confirm that I contracted HIV and Hepatitis C following Factor VIII treatment when I *"first had concentrate in 1980"*.

### Section 3. Other Infections

11. I do not know whether I was exposed to any other infections following treatment with Factor VIII.

### Section 4. Consent

12. My mother and I did not know that I was tested for HIV and Hepatitis C. I was tested without our knowledge and without our consent.

13. I refer to **Exhibit WITN1081005** which is a letter dated 14 October 1985 from Dr Ibbotson confirming that my blood tests for HTLV III had not been discussed with myself or my stepfather.

### Section 5. Impact

14. From the age of 18, I suffered from pains in my knee which meant that I dragged my leg around. I attended a consultation at Birmingham Hospital with Dr Wilde who was willing to operate. The pain became unbearable and I had to transfer hospitals as Dr Ibbotson did not wish to operate on me.

15. The first attempt at eradication of Hepatitis C following PEG Interferon and Ribavirin treatment was unsuccessful. I refer to **Exhibit WITN1081006** which is an extract of an undated letter from Professor Hay confirming that the relapse of treatment was *"complicated by severe, suicidal depression which persisted to a lesser degree once treatment finished"*.

## ANONYMOUS

16. In November 2016 I underwent the Sofosbuvir/Ledipasvir (Harvoni) and Ribavirin treatment for Hepatitis C. During the first week of treatment I felt fantastic. Subsequently I couldn't feel my arms and I could have stuck a knife into me and I wouldn't feel it. I suffered from aches in my joints, I couldn't move and started turning yellow. I constantly felt lethargic and suicidal. It was a horrible place to be in.
17. I refer to **Exhibit WITN1081007** dated 18 May 2016 confirming that I had cleared Hepatitis C following treatment with Sofosbuvir/Ledipasvir (Harvoni) combined with Ribavirin.
18. Approximately 10 years ago my HIV treatment affected my mental health negatively and I suffered from terrible depression. It was an injection which name I do not recall. I felt like garbage all the time. I am on different HIV medication and I am happy with the treatment regime provided to me by a hospital in Manchester. I refer to **Exhibit WITN1081008** which is a letter dated 8 March 2012 confirming that I suffer from chronic depression.
19. I suffered from a heart attack in 2012 due to lack of sleep. I suffer from arthritis and I take tablets which have suffered the lower parts of my heart. The doctors conducted some tests which concluded that I had suffered from a blood clot around my heart which is very unusual for a haemophiliac. I am on beta-blockers now. I underwent a knee replacement in 2000 and a right ankle fusion in 2008 to which **Exhibit WITN1081009** refers.
20. My health has been unstable throughout the years. I was not always able to work. When I got married my career was quite successful but Hepatitis C came with a vengeance. Following my heart attack I had to end my business and I got divorced.
21. My ex-wife and I went through sperm washing in Chelsea and Westminster which cost approximately £8,000. We took out a loan to cover this but it was unsuccessful. Subsequently I discussed this with my doctor who told me that by that point nobody has been successful so far and I couldn't believe that I wasn't told about that. It was unbelievable.

## ANONYMOUS

22. We got pregnant accidentally and we have children. My ex-wife and children are healthy and were not infected. Following the divorce I got full custody of our children.

23. I have had to give up going to the gym and I also suffer from stress bleeds which is why I was not prepared to put myself from having to provide a witness statement.

24. I began gene therapy and I am not a moderate haemophiliac. Prior to therapy my clotting factor was 1% and now it is up to 5%.

### **Section 6. Treatment/care/support**

25. I was offered counselling periodically. It's not for me though as I don't want to talk about it and I understand that everyone has bad days. As I get older I have learned how to live with what has happened. I don't want to open up and talk about it. I have got on with living and I don't use my blue badge.

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

26. The MacFarlane Trust refused funding for sperm washing. They advised that my wife had to go to a clinic in Manchester first to make her more fertile. They paid a tiny amount towards this treatment. A lady called Keisha at the MacFarlane Trust was really helpful and lovely. She would always get things done for us and she did whatever she could which was good.

27. I received monthly payments from the MacFarlane Trust which were £300. Approximately 15 years ago it increased to around £1,000 per month.

28. There was an announcement made prior to the Inquiry that the co-infected people (and there are around 119 of us left) would receive a total annual payment of £44,000 which was £12,000 less than if you added the other sums together which are £28,000 each. I do not want to be greedy but why is it a

## ANONYMOUS

discount for having both infections? We should be receiving £56,000. I do not know how they are getting away with this calculation.

29. I thought they finally realised what they did and that they were going to address it but they just keep letting us down at every opportunity.

30. Once the payments were released the increase in my payments amounted to a mere £200. The payments were inclusive of the top-up payment which is completely unacceptable. I was expecting to receive an increase of £1,200 a month. I was advised that the reason for this small increase was because just before the announcement was made, the top-up payments were included in the increase. This is the main reason why I am providing this statement to the Inquiry.

31. My total annual increase should have amounted to £14,000 but it is a mere £2,600.

32. Originally I received an income top-up, child supplement for three young children and the payment for infections. Due to the new payment scheme I am no longer receiving the income top-up. This was not worded like this and I wasn't made aware that they would be withdrawing some of my other payments. I just focused on the increase. They have done this because very few people are prepared to stand up and shout about it.

33. The EIBSS is another label hanging around my neck. It advertises my issues about blood. I spoke to someone at the scheme and he said there was nothing they can do despite many people raising this concern.

34. The MacFarlane Trust used to provide an allowance for domestic work such as when windows needed renewing. I requested this help and the lady directed me to my house insurance provider. She was extremely rude and didn't want to help as it was "public money". I explained that this money was reserved for people such as myself who have been infected for no fault of their own.

## ANONYMOUS

35. The application process and the telephone calls were difficult especially when suffering from ill-health. I believe the Trust should have been more available to help willingly and not putting ill people through more difficulties.
36. The MacFarlane Trust then gave their money to the Terrence Higgins Trust. Why did they give it to another organisation? I cannot believe it. It was shocking and continues to be a nightmare.
37. I received the Stage One payment from the Skipton Fund and I haven't heard from them since.
38. I was also involved in the US action against the pharmaceutical companies in 1991. I signed my rights away in the waiver. We were told we would get the pittance money and that we would not be able to sue the Government.

### **Section 8. Other Issues**

39. Every time there's an Inquiry or report it's all just churned up again. I just want to put it in a box and put it away and not deal with it all again.
40. My children do not know that I am providing a witness statement and I have kept my infections a secret for many years. I do not want to re-live the things which happened to me.
41. The only thing which has persuaded me to provide a witness statement is the sheer fact that injustice has happened and I am utterly frustrated that someone has got away with it for so long.
42. I cannot watch the Inquiry and the middle aged men trying to fight back tears. It is so powerful and so hurtful. I keep up to date but it is not the same as watching and being able to support them. I have to keep distant from the whole situation.
43. The only reason I have provided this statement is to express my grief about the lack of financial assistance and its pitfalls. It was never my intention to

## ANONYMOUS

provide a witness statement because my children still are not aware of what has happened to me but I feel compelled to provide a witness statement due to the imbalance of financial support.

### Anonymity, disclosure and redaction

44. I do wish to apply for anonymity.

45. I do not wish to provide 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

27/8/16