

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** of **GRO-B** My date of birth is **GRO-B** 1967.
2. This statement has been prepared without the benefit of access to my medical records.

Section 2. How Infected

3. I have severe Haemophilia B.
4. I received Factor IX from birth at the Haemophilia Centre at the University Hospital in Cardiff. My mother also oversaw my home treatment sessions and my consultant was Professor Arthur Bloom.
5. I was infected with HIV and Hepatitis C as a result of receiving contaminated Factor IX.
6. I was not given any advice or information in relation to the risks of receiving Factor IX.

ANONYMOUS

7. I had a meeting in the evening of 12th July 1985 with Professor Bloom when he advised me that I had contracted some form of Hepatitis and also HIV. I recall that he mumbled a lot and I did not pay much attention to what he said. One of my brothers and my sister accompanied me to the specially arranged appointment. I remember coming out of this appointment a bit confused and it was only when I heard one of the staff nurses questioning whether I should be injecting myself that the penny actually dropped.
8. In my view, I was not given sufficient information to allow me to understand or manage my infections of HIV and Hepatitis C. I was not given any information in relation to the risks of transmission.
9. Sometime in the 1990s I recall attending a routine clinic appointment at the same Haemophilia Centre in relation to my HIV when I was, in my view, fully advised about the nature of what being infected with Hepatitis C meant. I saw a registrar at this hospital, whose name escapes me, and he did fully advise me about how to deal with my Hepatitis C.

Section 3. Other Infections

10. I recall receiving about 3 or 4 letters which advised that I had received blood products from a donor who had been infected with vCJD.

Section 4. Consent

11. I was tested for HIV and Hepatitis C without my knowledge or consent. I used to ask the registrar why he was taking my blood all the time and he always replied that it was just routine procedure.

Section 5. Impact

12. The meeting on 12th July 1985 changed the course of my entire life. I attended this appointment with one of my brothers and my sister. We all came out of Professor Bloom's room and walked down the corridor in total shock.

ANONYMOUS

13. My brother said *"well I have got one of the diseases"*; he was infected with non A non B Hepatitis (as it was known at the time) and I said *"well I think I have got two of them"*. My sister said that my nephew had also been infected with two diseases.
14. I had not fully appreciated the seriousness of what Professor Bloom had told me. I never really spoke about it again with my siblings.
15. I do remember returning home after that dreaded meeting aged 17 and my mother started play fighting with me as soon as we all walked through the door. My brother shouted *"make him bleed why don't you"* and I said *"that's right tell everyone why don't you"*.
16. I remember running upstairs and my older brother who does not have Haemophilia followed me and asked me what was wrong. I said *"I think I have been infected and am going to die"*. He reassured me whilst fully appreciating the severity of my diagnoses.
17. I dealt with how I felt on my own because my father died when I was aged 16 and my mother just felt guilty. I could have turned to my four siblings but I chose not to.
18. I confided in one friend who I thought was a close friend but he was really shocked and gave me absolutely no support.
19. I withdrew from all activities and became very bad tempered. I was very cautious with girlfriends.
20. Physically I suffered from night sweats, eczema and very bad skin.
21. I took a concoction of antivirals in order to keep my HIV at bay but the side effects were horrendous. These caused a worsening of my symptoms and bad diarrhoea.
22. I commenced a 48 week course of Interferon for my Hepatitis C and experienced the most horrific side effects. It was like having the most severe form of flu for the entire duration. I cannot recall the date but I know that I managed to endure the full course. I was advised that I would possibly need a blood transfusion whilst on the course but I ended up requiring 14 because I was so poorly. However, following completion of this course I cleared the virus.
23. My schooling suffered due to my infections and I have never been able to work. I have therefore struggled financially.

ANONYMOUS

24. I lived with my mother until I was aged 21 at which time I was able to move out and become a little more independent.
25. I have always kept my infections secret because on the one or two occasions when I disclosed the same it backfired on me. I remember being out one night with a girl and then arranging to meet her again a few nights later. However, in the intervening period the person who I thought was a close friend and as such had confided in, had told her about my infections. Following this, she said that she no longer wanted to see me.
26. My wife came from a small village and when I met her someone had said to her step-daughter "*what is your mother doing with him, he has HIV*". My wife already knew so it was ok and when my step-daughter questioned her mother, her mother denied it because she wanted to respect my wish not to tell anyone. I feel very grateful to her for the action she took in this regard.
27. However, my mother comes from a large family and she told my cousins about what had happened and left it up to them as to whether they continued to visit our house. The visits continued which was one positive outcome of this tragedy.

Section 6. Treatment/Care/Support

28. I am always last on the list for operations and no reason is given for this.
29. I also recall a time when I attended, with my ex-brother in law, the Haemophilia Centre in Cardiff in respect of a severe toothache. The registrar openly referred to my infected status in front of my ex-brother in law which was entirely unacceptable, inappropriate and breached patient confidentiality.
30. Eventually I managed to get my own dentist although he does wear a full face mask when treating me.

Section 7. Financial Assistance

31. I have received financial support from the Macfarlane Trust including grants for new windows and a driveway for my house. Sometimes applications I put forward were agreed and sometimes they were not.

ANONYMOUS

32. I did not like begging and that is how the Macfarlane Trust made me feel.

33. Initially the process of applying for grants wasn't too bad but as time went on, it became more convoluted and difficult. I had to submit receipts and provide a number of quotes for each request.

34. I received regular monthly payments from the Skipton Fund and I also received the Stage 1 payment of £20,000.

35. I also received a winter fuel payment although I believe that this was stopped last year.

36. Currently, I receive about £2,130 per month from the EIBSS.

37. I was a party to the HIV litigation that ended in 1991. I received a number of payments in this regard and I believe that the initial payment was £25,000, the second was £60,500 because I was living with a partner and had step-children and the third was £20,000.

Section 8. Other Issues/Conclusion

38. I want answers from this Inquiry. I want to know who was responsible and why they were allowed to do what they did. People need to be held accountable and sent to prison. Apologies are insufficient.

Anonymity, disclosure and redaction

39. I do wish to apply for anonymity and I do not want 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**

Dated..... 18.3.2019