

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1138001

Dated: March 2020

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 I was born on the GRO-B and live at GRO-B with my girlfriend. I have worked as a chef for the entirety of my adult life.
2. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

3. I suffer with Hemophilia A classed as severe with a blood clotting level below 1%. I was diagnosed in the first year of my life as I bruised very easily, at first Social Services became involved as it was thought I was being abused

ANONYMOUS

4. I was treated at [GRO-B] in [GRO-B] under the care of Doctor [GRO-B]. I have also received treatment at the [GRO-B] [GRO-B].
5. I received Factor VIII (FVIII) as and when I required it. When I was around 10 years old I started administering Factor VIII myself at home.
6. I believe I received contaminated FVIII in 1982, however some records state it was actually 1984.
7. My parents were not provided with any information or advice beforehand about the risk of me being exposed to infection from blood products. The first time I heard about the possibility of being infected from FVIII products was through the Haemophilia society, when I was a small child. My father confronted Dr Martin about his concerns of possible infection, but Dr Martin laughed and made remarks about 'not being silly'.
8. I was infected with human immunodeficiency virus (HIV), Hepatitis B and Hepatitis C (HCV) as a result of being given contaminated blood products.
9. My mother found out I was HIV and HCV positive in 1984. The hospital called her and informed her of my infected status over the phone. My mum then informed me that I was HIV positive on my thirteenth birthday but she did not mention that I was also HCV positive. I was not informed directly by the hospital about being infected with HIV or HCV as I was under the age of 16.
10. My mother was not provided with adequate information to help us understand and manage the infection. She was only warned of the stigma associated with having HIV.
11. I believe adequate information should have been provided to my mother and I, and we should have been advised on how to deal with the infection earlier.

ANONYMOUS

12. The way information was provided to my parents was terrible and we had no support when I was growing up. My parents were told by the doctor that I would not live past 8, and then when I did, they said I would not live past 13.

13. I was not provided with adequate information about the risk of others being infected as a result of my infections. The first time I was warned of the risks was when a social worker sat me down with two other boys and gave me a packet of condoms and said that HIV could be passed on through sex.

Section 3. Other Infections

14. I am at risk of being infected with vCJD as my records state I was given a batch of FVIII which was possibly contaminated with vCJD.

Section 4. Consent

15. I believe I was tested and treated without my knowledge, consent and without being given adequate or full information. My parents did not provide consent for the HIV or HCV tests.

16. I also believe I have been tested for the purposes of research. I would provide vials of blood and I would ask the nurse where the vials were being sent to and she would just state 'Oxford'. I believe they were using these vials to try and find cures.

Section 5. Impact

17. Being diagnosed with HIV and HCV has destroyed my life: the damage is beyond repair. It is the psychological elements that affect me the most and

ANONYMOUS

I have previously regretted still being alive. The stress of my diagnosis has also lead to me abusing alcohol in the past.

18. The infections have also affected me physically. I suffered from severe weight loss to the degree that I looking like a skeleton, my teeth have crumbled to nothing and I currently have post-traumatic stress disorder.

19. I worry about the implications of taking tablets everyday, as it will have an impact on my liver and kidneys. Some combinations of the tablets I have had to take have psychologically tortured me.

20. I currently have scarring on my liver.

21. I was treated with Interferon at the GRO-B when I was 18 to clear the HCV but. I was only on the treatment for 2 months before I had to stop as it was making me feel very sick. My family wanted me to continue with the treatment but I felt like this was not an option for me at that time.

22. I was later treated with a newer form of HCV treatment, which I cannot recall in the name of. I was on that treatment for four months and fortunately I tested negative for HCV in 2017.

23. I have been on azidothymidine (AZT) medication to treat the HIV from 1991 to 1997. As a direct result of the AZT treatment my teeth fell out, I suffered with insomnia and chronic fatigue.

24. Various dental surgeries have refused to treat me in the past because of my Haemophilia; as a result I go to the GRO-B Hospital for treatment

25. Being diagnosed with HIV has had a massive impact on my social life. I have alienated myself, because I cannot tell anyone about my condition. When I was younger I remember being told I could not play with my cousins in case I infected them as well.

ANONYMOUS

26. Another big impact has been that because I thought I was not going to live very long I have not had any children. If you believe you are not going to live long enough to raise your children it prevents you from even thinking about it.
27. My ex-girlfriend contracted HIV from me. When I found out I was devastated. I feel that my life has just been a trail of destruction.
28. I do not tell people about my infected status because of the stigma. The stigma is massive, and it still occurs in 2018. If I died, my parents were advised to tell people I died from leukemia because the stigma would be bad if they said I died from HIV. I think this is immoral and disgusting.
29. Having HIV impacted on my education greatly. Once I knew about the HIV I did not want to go to school, I did not see the point if I was going to die. However when I was 16, I did go to college to train to be a chef.
30. The impact on my work has been noticeable. Even though I am able to work as a chef, I will probably have to give up work in the future because of my arthritis. I believe if I did not have HIV or HCV I would have worked harder to advance my career, but I have just completely lost my confidence. I also had to stop working when I was on the interferon treatment.
31. The impact on my family has been catastrophic. My infected status has affected my father a lot. It had a big impact on his work as he had to quit his job in order to look after me. Moreover, my infected status has affected my father's family life as his family treated me so badly, my father felt he could not even have a relationship with them anymore; they have not spoken in over thirty years.

Section 6. Treatment/Care/Support

ANONYMOUS

32. The psychological support that has been offered to me by the NHS has done more harm than good. When I needed support, it was not available; I was always just put on a waiting list.

Section 7. Financial Assistance

33. I received financial assistance from the Skipton Fund when I was eighteen years old. I receive £1300 a month for the HCV which I have received since April 2018. I do not get a top up because I currently work.

34. The process of applying for the fund was embarrassing. I wanted to apply for a grant (for a bed) but I could not bring myself to apply because I was too embarrassed.

35. I also found the process of applying to Skipton very difficult.

36. I applied to the SCM scheme, in respect of the HCV but I was refused the first time; however I reapplied and was accepted. Applying for the SCM scheme was like trying to get blood out of a stone. You had to jump through so many hoops.

Section 8. Other Issues

37. I have waited twenty four years for someone to hear my story and it is about time that the Government paid us fair compensation for what they have put us through

Anonymity, disclosure and redaction

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

Statement of Truth

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

Signed

GRO-B

Dated

29/4/20