

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1533001

Exhibits:0

Dated: March 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. I was born on GRO-B and I live at GRO-B.
GRO-B
GRO-B
2. I am currently single and live on my own. I am not working.
3. My mother passed away GRO-B years ago in GRO-B. She spent a lot of time and effort campaigning for justice for victims who were affected as a result of the contaminated blood scandal. She was my main carer when I was treated with Factor VIII (FVIII) and infected and she took care of my medical appointments.
4. GRO-B.
5. 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

6. I was diagnosed with severe Haemophilia A when I was GRO-B. I have 0% clotting factor. I underwent a lot of treatments for my Haemophilia as a child.
7. I initially received Cryoprecipitate at GRO-B and then I started to receive FVIII and I believe it was in the mid 1970s when I was transferred to GRO-B.
8. My treating doctors at the time were GRO-B and GRO-B.
9. My mother administered FVIII to me when I was a teenager around the early to mid 1980s. I had a big fear of needles and so did not like to self-administer FVIII. I got away with not having FVIII on a regular basis and would only have it on average once a week.
10. As a result of the FVIII, I was infected with HIV and Hepatitis C (Hep C) and Hepatitis B (Hep B).
11. The doctors did not tell me or my mother that I was at risk of having HIV until my mother asked them in the mid-1980s after hearing about it in the press and newspapers. The response from the doctors was that there was a possibility that I may have been infected with HIV. My mother insisted that I have a blood test for HIV, which I did.
12. After my blood test, I were called to speak to a doctor. I was only about 13/14 years old when the doctor told me that I had tested positive for HIV. He offered me condoms, which I found to be very strange. I was very young at the time and very confused about what I had been told. I was not provided with any further information about it.
13. I became more aware of the infection by reading about it in the newspapers and seeing the television adverts. I was very sceptical about what I was being told. The information I was given was very poor. I spent many years after this confused about what I should do and what was going to happen. I did not

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really take it in straight away. It was not until I was older and got into relationships that I understood how HIV would affect me and others around me.

14. In the early 1990s, I attended a routine appointment for my Haemophilia. It was at this appointment that the doctor casually said that I also had Hep C. I remember responding saying I did not know anything about having Hep C, this was the first that I heard I had it. I have only really come to terms with it in the last 4 or 5 years. I never had any consultants or liver specialists prior to that to advise me and help me manage the infection. I was told about 4 years ago to watch my alcohol and to have safe sex.

15. I also found out at the same time that I had Hep B, but it cleared by itself. I was not given much information about this. I had no idea what the doctor was talking about.

16. I do not believe that I was given adequate information to help me understand and manage the infections.

17. I believe that information should have been provided to me earlier when the doctors first found out that I had been infected.

18. I was provided some information about the risks of others being infected as a result the infections. As previously stated, I was offered condoms at my first appointment.

19. In or about the mid 1990s, one of the haemophilia nurses said that there was a higher risk of passing Hep C than HIV but the doctors did not tell me this themselves. At the time I was more concerned about the HIV than Hep C.

Section 3. Other Infections

20. I received a letter in the early 2000s from the hospital stating that some of the batches of FVIII that I had received were infected with vCJD. I was subsequently tested and thankfully I was not infected.

21. I also had [GRO-B] twice which I believe was directly related to the Hep C.

Section 4. Consent

22. I believe that I was treated and tested without my knowledge and consent. Before I raised a question regarding the HIV or Hep C, the doctors seemed to already know the answer, as if they already knew what was going on with me.

23. I believe I was also treated and tested without being given adequate or full information. I was never provided with much information unless I asked for it. I am still asking questions now in relation to the infections as some of the answers that I have received are still not clear. The doctors are not very forthcoming.

24. There is a possibility that I was tested for the purposes of research but I am not sure.

Section 5. Impact

25. I suffered mental effects as a result of the HIV. When I was at school, there were several teachers who were fighting for me to be removed from school. I was declined from the classroom in the [GRO-B] even though I did exceptionally well in it and I was very interested in it. The teacher said the reason why I was declined was because they only picked top students, which I believe I was. I never got the chance to do that subject. That was the first sign of prejudice that I received. The HIV infection impacted me psychologically and mentally more than it did physically.

26. Finding out about the HIV was more of the bombshell and finding out about the Hep C was like an aftershock. I did not treat Hep C seriously as I did HIV; at the time HIV was all over the newspapers and was a well known infection to everyone.

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27. As a result of the Hep C, I believe I suffered from [GRO-B]. I had [GRO-B] in [GRO-B] and [GRO-B], and being HIV positive, [GRO-B] was very complicated for me. I also had to have one knee replacement and 2 ankles fused due to excessive bleeding into joints.

28. In the early 2000s I was given a combination treatment of Combiver and Neverapin for the HIV. This treatment has slightly changed now to accommodate the Hep C treatment.

29. In or about 2016, I was offered Harvoni treatment for Hep C. It was a 12 week course. The treatment initially cleared the Hep C but it came back later that year. I am now on a second course of treatment consisting of Osevi which I started in February 2019. This is a 12 week course.

30. I faced difficulties in accessing the Harvoni treatment for the Hep C. I was initially offered the treatment in 2014. However, due to the financial restraints, I was pushed to the end of the list as they were only giving the treatment to those whose livers were worse than mine.

31. I had depression as a result of [GRO-B]. I would not have had to have [GRO-B] in the first place had it not been for the Hep C which caused the [GRO-B].

32. I believe my infected status has impacted upon my dental treatment. During the [GRO-B] treatment, my teeth were going bad, but I was not allowed to have my teeth checked whilst I was on the treatment.

33. In the early 2000s, when I was having [GRO-B], I asked a doctor the about the possibility of sperm freezing. I was rudely told by the doctor that they did not want my sperm as there was a chance it could infect others. I was basically told it was a complete waste of time. I then asked about the possibility of sperm washing to which the doctor was very negative about it and said it was not very reliable. However, I have been in contact with someone who I went to school with and he said he has two children through sperm washing. I feel upset that the doctor gave me the wrong advice back then. I now regret not looking further into sperm washing. As I have had

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GRO-B twice, the chances of me having children are very small as it is likely that the treatment has damaged the sperm.

34. The infections impacted on my private, family and social life. When I was a teenager, other children were making fun of me and teachers did not want me in school. In the 1980s, HIV was very misunderstood as there was a stigma attached to it. I was unable to have a social life and I was unable to have proper relationships which upset me. There was always a risk of me passing the infections to my partners which hindered my chance of getting close to anyone.
35. There was definitely a stigma attached to the HIV at the time. HIV was all over the newspapers and television adverts. As a child, it made me very upset to see them. Even till this day, I do not tell anyone about the infections as I do not want people to think differently of me. I have only just started to get in touch with people from school. Even though HIV is now socially more accepted, it still plays at the back of my mind about what people would think of me.
36. The infections had an educational effect on me. I did not go to college or university. As previously stated, I was not allowed to continue with my favourite subject at school. I would have loved to pursue a career in **GRO-B** and I believe I could have, had it not been for the infections.
37. I have also suffered work-related and financial effects as a result of the infections. I was worried about finding a job due to the stigma attached to the infections. I always felt that if any of my employers found out that I had HIV, I would be pushed out of my job or get bullied. As I got slightly older, the effects of the infections started to kick in and I started to become more lethargic and have more pains. I therefore had to stop working.
38. My mother was severely impacted as a result of the infections and was very upset. As previously stated, she went through so much for me and put in a lot of time and effort to campaign for justice regarding this scandal. She passed away without seeing an end to this. I know my mother had a lot on her mind

but she would just deal with it without showing her emotions to me. My mother was a very private person and hardly spoke to me about it. She was always a positive person and liked to deal with the situation one day at a time. I knew that she was very angry, hurt and upset about what had happened to me.

39. My [GRO-B] was a young child at the time. My mother told me that [GRO-B] was once taken to the doctors after bedwetting and the doctors said that it was the stress and worry about me which caused it.

Section 6. Treatment/care/support

40. I faced difficulties in obtaining treatment, care and support in consequence of being infected with HIV and Hep C. I was never offered treatments until my first [GRO-B]. I had shingles twice and was more or less left to treat it myself. I was just given treatment and just told to come back after 6 months.

41. Approximately 2 or 3 years ago, I was asked to see a counsellor as my mother was seriously ill and she could no longer administer FVIII to me. As previously stated I had a fear of needles and so I was provided counselling in order to get over this fear. I only started self-administering FVIII 2 or 3 years ago.

42. I was not provided counselling regarding the infections. I believe I should have been offered counselling especially when I was a teenager as I was going through an awful lot of emotions. I was in a bad place as a teenager and was left to deal with it on my own. There was no support for me, which is appalling.

Section 7. Financial Assistance

43. I was party to the litigation in 1991. I received £55,000 from the Macfarlane Trust when I was 17 years old. My mother dealt with this on my behalf.

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44. In the early 2000s, I received two payments from the Skipton Fund. I received the Stage 1 payment of £25,000 and the Stage 2 payment of £25,000. I did not apply for these payments, they were both sent to me automatically.
45. In or about the early 2000s, I asked the Macfarlane Trust for help to buy a house, which I had to fight for. They initially gave me £63,000 as a loan and later increased the loan to £70,000. The process was quite difficult. They put a charge on my property in a percentage rate instead of a price value, as the property value increased. They are now charging me interest which is increasing gradually.
46. I also applied for a grant towards a new vehicle, but it was turned down by the Macfarlane Trust. Instead they offered money to have my old vehicle repaired, which I eventually received after 6 months. I have struggled so much with Macfarlane Trust.
47. Every time I apply for financial assistance, I constantly get turned down. I always have to go through the appeal process and on occasions some of the applications have been accepted.
48. Previously, my mother was receiving monthly payments which she used to transfer to me. I had received and continue to receive from the EIBSS just under £2,000 from the Macfarlane Trust and £1,500 from the Skipton Fund.
49. It is such a battle to get any financial assistance. Other people that I know have received more than me.
50. I was told that on average people were getting about £9,000 in grants. I applied for a grant towards my heating as it required repairs, but it was a battle trying to get the money. It happened in the winter months so it was not very pleasant waiting for the grant.
51. I am having treatment in GRO-B, which is approximately 1.5 hours away. I have to pay for travel and even though I can apply for financial assistance, I believe it is not worth the hassle. I believe that they should have offered it to me themselves.

Section 8. Other Issues

52. A friend of mine found out he was HIV positive after my mother had a conversation with his mother. They then went to the hospital and got him tested. I cannot believe this was how he found out that he had HIV. The communication between the hospitals and their patients were non-existent. Everything was handled in an inexcusable way.

53. I want some answers from the Inquiry. My mother put so much hard work into campaigning for justice for those who have died and were infected and affected. Someone needs to be held accountable for what has happened because this scandal has affected so many lives in so many different ways.

Anonymity, disclosure and redaction

54. I wish to remain anonymous.

55. I do not wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed.....

GRO-B

Dated

4/4/2019.