

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3050001

Exhibits: WITN3050002

Dated: September 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 live at GRO-B
GRO-B My date of birth is GRO-B I am
single and I am currently unemployed.
2. I was infected with the Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV) as a result of receiving contaminated blood products. One of my brothers is also a haemophiliac and is also co-infected as a result of receiving contaminated blood products.
3. This statement has been prepared without the benefit of access to my 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

4. I was diagnosed with Haemophilia A when I was young. I understand from my father that there were a few incidents when I had bleeds that did not stop. One day when I was about 18 months old I apparently fell off a Tonka truck and split my lip. It would not stop bleeding and I ended up in hospital where it was diagnosed. At the time we were living in GRO-B; we moved to GRO-B just before my 5th birthday.
5. I attach at Exhibit WITN3050002 a copy of the only records I have received which appear to be treatment records recording the treatment and batch numbers I was given for bleeds although they do not appear to record the year in which I received them.
6. My father was trained in treating me and administering Factor VIII concentrate at home. I began treating myself when I was about 11 or 12 and thereafter managed my own injections.
7. I recall hearing about HIV but I thought it would never concern me. My brother, who is also a haemophiliac, didn't know much about it despite people discussing it when we went on holidays with the Haemophilia Society.
8. My father knew about my infection years before we were told. My brother had also been infected as a result of receiving contaminated blood products. We found out that we were infected with HIV and Hepatitis C in approximately 1992/3. To be honest I do not remember it being a surprise.
9. I recall a brief conversation with a doctor at GRO-B who advised me against having relationships. He told me not to worry because I would be dead by the time I turned 20. I do not recall being given any other advice.

Section 3. Other Infections.

10. In 2003 I suffered from a brain infection which caused a suspicion about having been exposed to the risk of vCJD. However, this is not something that someone ever discussed with me in detail but has always been at the back of my mind as an additional worry.

11. I am not aware of any other infections.

Section 4. Consent.

12. I have never considered whether I have been treated or tested without consent. I have had so many tests over the years. I have had my suspicions about vCJD and I wonder whether this has contributed to my mental state. In 2003, when I suffered from encephalopathy, I wondered whether there was any link with CJD but this was not something that was discussed with me; it was just at the back of my mind.

Section 5. Impact

13. Whilst I was at school I was not really affected and it was only when I started in the sixth form at [GRO-B] that I started becoming more aware about my infections in terms of not having relationships. This became a much bigger deal when I went to [GRO-B] to study [GRO-B] between [GRO-B]. When I met people I struggled with the fact that I was not allowed to get too close to them. It impacted my social life at University and impacted any potential relationships but it did not prevent me from making friends.

14. I kept my infections a secret which made me feel like a fraud. I felt that I could never be 100% honest with people especially 20 years ago when I had no

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idea how people might react. I couldn't tell anyone because of the stigma associated with HIV and Hepatitis C at that time.

15. During my time at University I do not recall being ill apart from suffering with arthritis in my ankles as a result of my haemophilia.

16. I studied [GRO-B] which I started with a foundation year at [GRO-B] [GRO-B]. The course went from being easy to being very difficult and in [GRO-B] I transferred to [GRO-B] and was able to study my degree in a much more relaxed environment.

17. After University, I moved back with my parents and started working for a [GRO-B] [GRO-B] company in [GRO-B] called [GRO-B]. It was a really good office and I was thrown in at the deep end which meant that I learnt so much whilst working there. Unfortunately, I fell out with my boss a little and he made it impossible for me to continue working there.

18. I think the stress of my infections had started rearing their head and I felt like I was going crazy.

19. I thought it was just stress so I took time out and went to visit my brother [GRO-B] in Australia for a few weeks.

20. I also applied for other jobs and went for an interview in [GRO-B] where I was offered a job with [GRO-B]. I started with them in the summer of 2003.

21. During this time I lived with a friend from [GRO-B] and it was a lot of fun.

22. I think as a result of the stress from my previous job and the long flights to and from Australia I picked up a brain infection. It had remained dormant until the end of 2003 and then my immune system dipped and I had a seizure. I didn't even know that I was epileptic at this time. My friend called an ambulance.

23. I woke up two weeks later without my front teeth. This episode didn't affect my job and my employer was very good about it; I was able to go back to work after a few months. This fit had happened whilst I was doing a structural

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engineering module with the company which every new employee had to complete. I had missed quite a lot of the work but I still passed. I was started on Epilim.

24. I had been staying in a shared house but in December 2004, I bought my own flat and everything was going well.

25. In 2005, at one of my regular appointments with the HIV specialist they noticed a lump on my groin. I had to ring work and say that I was being kept in hospital; they were really good about it.

26. I was taken into [GRO-B] who initially told me that I was suffering from TB but after a couple of weeks I was diagnosed with lymphoma.

27. I underwent chemotherapy to treat the lymphoma but I was still able to work.

28. In 2007, I suffered from another seizure; this time at work. Nobody knew how to call 999 from the office as they had never done it before. Following this incident, I felt fine for a while again and life and work continued.

29. In 2010, a new neighbour moved in upstairs. It was a nightmare. He stomped around and slammed doors early in the morning to late at night which affected my mental health. I couldn't relax. I tried to reason with him for months but it became obvious that there was no reasoning with him. The owners of the building had no interest in this dispute. I felt completely abandoned. I started drinking alcohol every night as it was the only way I could cope. It led to depression and anxiety. I wasn't too aware of this at the time.

30. When I was seeing the HIV specialist at [GRO-B] I saw one of their psychiatrists. It didn't help as she just didn't understand that a lot of what I was going through mentally related to the HIV.

31. In 2012, after doctors had attempted to prescribe me antidepressants for a while, I finally gave in and started taking them as I felt pretty suicidal at this point. I was still able to hold the job down whilst taking Sertralene tablets.

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32. In 2014, my half sister [GRO-B] died. It was a wake up call in terms of dealing with HIV and re-evaluating my life. I was busy working between the [GRO-B] office and [GRO-B] and I was drinking. I ended up having to stay in hospital for two weeks because of it and I started seeing a psychiatrist at the [GRO-B] [GRO-B] and the [GRO-B] which was really helpful.
33. Towards the end of 2015, I told my employer that I had HIV and Hepatitis C. I was still very depressed and work was not going well. Things started falling apart. I started missing work and staying in bed. I stopped going to work completely at the beginning of 2016 and I ended up in a very bad way with depression and drinking.
34. I was admitted to hospital again and it was at that time that my parents got involved and introduced me to the [GRO-B]. They were really good and I started going to meetings there.
35. I underwent a detox summer in 2016. Following this there was a problem with my prescription for the detox drugs and I ran out of them. I went back to my old ways and I started drinking again. In 2017, I underwent a second detox and as a result of the drugs they were providing to me I was able to stop the Sertraline which I had become dependant on. This helped me to stop drinking alcohol.
36. I began volunteering through the [GRO-B]
37. In 2017, I went to college as I had enough of sitting around. My depression still had an effect on my daily life as I didn't do as well as I should have in my studies at this point but I still managed to pass a course in light vehicle maintenance and repair.
38. I attempted Interferon treatment in approximately 1993/4 which didn't go well. I could not continue taking it as my body rejected it. I had to inject my stomach sub cutaneous but my skin turned tough and I couldn't get the needle in. The doctors were aware that I was not going to try again until a new treatment

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came out and also they could not give me a new treatment whilst I was drinking heavily.

39. I started antiviral medication for HIV in 2004 and initially suffered side effects of swelling to nipples and chest area, feeling nauseous and was unable to continue to take them. I have had different combinations over the years but I am now settled on the antiviral treatment.
40. In the middle of 2018 I became very jaundiced with yellow eyes and skin. I was kept in hospital for a while but the jaundice cleared itself up. At the end of 2018 I eventually received treatment for HCV.
41. I began Harvoni treatment which I finished at the start of this year and I have now cleared Hepatitis C. I had to take one big tablet and two smaller ones but this wiped me out so they changed the medication to one big tablet and one small one.
42. I will continue to have check ups and my next check up is in October 2019 for a final meeting with the doctors which will hopefully be the end of Hepatitis C for me.
43. I am currently unemployed but I continue to do bits and pieces of volunteering from time to time. I completed a bicycle maintenance course earlier this year which I hope will lead to something bigger and I am feeling more optimistic than I have felt for a little while.
44. I am still struggling with anxiety and depression but I am hoping that once I get back into regular work it will help. I have never felt that because of my infections I could have a proper career. I seem to drift along rather than aim for something.
45. The infections have massively affected my motivation and self confidence and I have felt like I have been unable to plan for the future. At times I feel I am not living, just waiting to die. It was difficult whilst I was working in GRO-B not with my bosses per se as they knew that I would make up the time, but it affected my relationship with my co-workers as they saw me taking a lot of

time out to attend hospital/doctors appointments. I felt like a bit of a fraud not being honest with people.

46. Since I have left work I told a few of my friends about my HIV and HCV and they have been very supportive.

47. I have started to realise there is still stigma attached; not particularly amongst my friends but I hear things that people say on the streets which make me realise that it is still a big thing for some people. I feel that I cannot be open or honest with everyone.

48. HIV and HCV have stopped me from building a proper relationship; I think I have built up barriers not to get close to someone. The psychological effect has been huge; I don't really think that people understand. I feel that my employers in GRO-B were almost too supportive to the extent that I felt that I have let them down.

Section 6. Treatment/Care/Support

49. My first attempt at seeing a psychiatrist was a failure. She didn't understand that a lot of my mental health issues stemmed from having been infected with HIV and HCV.

50. Following my GRO-B I began to see a psychiatrist once more from the GRO-B and I found these sessions very helpful.

Section 7. Financial Assistance

51. I received compensation following the HIV litigation through the MacFarlane Trust which went towards buying my flat. As I was too young at the time my father dealt with this and gave me the money when I bought my flat. I do not

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know if he signed the waiver but I believe that he must have done to receive the money.

52. I have received stage one and stage two payments from The Skipton Fund.

53. I do not receive benefits because I receive payments from the EIBSS. These have recently been increased as a result of the Inquiry.

54. Since July 2019 I have received monthly payments of £3,666.

55. I have been receiving monthly payments for about 10 years from the Skipton Fund and I have also received payments from the MacFarlane Trust which was approximately £1200 per month for 8/9 years.

56. I did have some problems with the fund over a couple of years when I had to reapply every year. This was a worry for me but now it is hugely reassuring knowing that I have those payments every month.

Section 8. Other Issues

57. I would like transparency and honesty about what has gone on over the years; this should never have happened in the first place.

58. I think that over the last few years it has been mentally reassuring to receive monthly payments. I think this has saved my mental state to some extent because I think if I had to have claimed benefits it would have finished me off.

Anonymity, disclosure and redaction

60. I wish to remain anonymous and I understand that this statement will be published and disclosed as part of the Inquiry.

61. 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... 24/09/19