Witness Name: GRO-B
Statement No:WITN2717001
Exhibits: 0
Dated: 15 February 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 the GRO-B. I live at GRO-B I have GRO-B GRO-B

2. This witness 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

3. On the GRO-B, I was involved in a serious road traffic accident and was admitted to GRO-B for treatment which included a blood transfusion.

4. As I was not aware I was having a blood transfusion I was not told of any risks.

5. I was infected with Hepatitis C (HCV) as a result of being given contaminated blood products through the blood transfusion.

6. In approximately GRO-B, I returned home from college to find GRO-B GRO-B GRO-B GRO-B a batch of infected blood had been used for the transfusion I had been given and it was likely had been infected with HCV. My sister told me that HCV was 'something like AIDS'. GRO-B left me with a leaflet titled 'Health for Travellers'; and advised me to get a blood test.

7. I read the leaflet, which contained details of many ailments one could contract when travelling abroad. Finally, the last page had a section on hepatitis, with only the last sentence mentioning HCV. The statement read 'an incurable sexually transmitted virus resulting in chronic inflammation of the liver'. At the time I remember thinking that I did not know what 'chronic' meant but it did not sound good and I hoped someone would tell me soon.

8. I had a blood test and received, in the post, a referral to a liver clinic in the GRO-B I arrived for the appointment and was asked to undress and lay on the bed. I was asked if I minded if student doctors were involved in my case and I said I did not mind. The curtains were closed around me and I

undressed and laid on the bed waiting. Presently, the curtains were open and ten or more students surrounded the bed. I felt extremely embarrassed and intimidated. The consultant proclaimed loudly, 'you are not meant to be naked'. Without a further word to me, he turned to the students and said 'so, who can tell me what is wrong with this patient'. After some questions and answers the conclusion was HCV. He asked what the treatment was and a student answered 'there is not one'. He asked the prognosis and the same student answered 'chronic inflammation of the liver'. They all then left leaving me on the bed.

9. The nurse, looking very worried, apologised repeatedly for me having asked me to undress. She told me I could dress and closed the curtains. I dressed and waited some time for someone to come back. After around half an hour I ventured outside the curtain and finding no one around I asked a nurse passing in the corridor if I should wait further. She advised me that the rounds were long over and I should go home. I walked home shocked and shaken and going over in my mind what the word 'chronic' might mean.

10. With little information to go on I reached the conclusion that all of this must mean that I was going to die from this. The only thing I had to go on was the fact 'it was a bit like AIDS', which I knew about, and that it was incurable and chronic, whatever that meant.

11. I never spoke to the doctors about HCV; no body actually sat down and spoke to me. I was left to assume and sort it out myself. Nobody ever spoke to me about what this disease was, how I had been given it, what would happen or how long I had left to live. Given nothing to go on and not feeling unwell at the time, I just carried on. Over time I managed to piece all the new information I was given and get an idea of what I was up against.

12. Ultimately, after moving to GRO-B to go to University, I was referred to a clinic in GRO-B, where I was treated much better.

13. I was less than impressed with how I was told and the information that was provided. GRO-B GRO-B

14. I was not told about the risk of others being infected. Other than the one leaflet that said it was sexually transmitted. I therefore broke off all relationships for the next seventeen years and lived more or less in isolation.

Section 3. Other Infections

15. I have not been infected with anything else other than the HCV as far as I know.

Section 4. Consent

16. I do not believe I have been tested without my knowledge or consent.

Section 5. Impact of the Infection

17. I was shaken with no one to turn to for advice when I found out about my condition. As a result, I made an appointment with a counsellor in my college. I had to wait two weeks for the appointment; that passed in a complete haze. By the time I spoke with the counsellor I was a wreck. I briefly explained what I had been told and showed her the 'Travellers Health' leaflet I had been given. Unfortunately, she advised me that her role was typically to advice about collage programmes. She went to speak to a colleague and on returning, advised me that to the best of their knowledge HCV was 'a bit like AIDS'. She recommended I drop my programme studying GRO-B and think about doing something less demanding with the time I had left. She suggested university was probably not a realistic ambition for me.

18. The physical side effects of the HCV were that I was very tired and drained for long periods. I had to go for biopsies every five years which I kept very secret. I would move my lectures, have a biopsy, and then return to my course work. I had bowel problems as well; as a side effect of the treatment.

19. The Inquiry has caused me to go back over things. I have Post Traumatic Stress Disorder, anxiety and depression. It is only now becoming apparent that I have been depressed for the best part of twenty years.

20. In the GRO-B I was told that my biopsy results showed a significant increase in the fibrosis in my liver. It was explained that the risks associated with the treatment were now acceptable (compared to the alternative). Given the evidence at the time (for my Geno type), I was given a less than one in ten chance of success, so I had to think really long and hard about whether to have the treatment and give up the quality of life in which were very likely to be my last years of my life. I resolved to give it a go. The treatment I received was interferon and ribavirin, which I started in around 2007. I had to inject myself every week for forty-eight weeks.

21. The treatment was gruelling. Injecting myself on a weekly basis with interferon made me very sick. The side effects were horrible, I felt like I had flu all year. Much of my hair fell out and I struggled to hide my condition from my employer and my students. Around half way through the treatment, my skin started to break out in blisters (which resulted in me being hospitalised) and I continuously bleed from my bowels. It was a year of a lot of self contemplation. The treatment however, despite the odds, was a success; but it has left me with significant ongoing health problems.

22. I have a bowel disease from the interferon treatment; that now requires ongoing treatment with immune suppressants. The bowel disease also causes kidney

stones and I have to have skin cancer removed regularly because of the now necessary treatment with immune suppressants.

23. I developed Crohn's disease as well, it is not conclusive that this was from interferon but it came on when I was having interferon treatment and there are papers showing a link between ribavirin and Crohn's disease.

24. I believe treatment was withheld because I would not consent to join a research programme. When it was first identified that I had reach the stage of chronic liver inflammation (fibrosis) I was only offered the option to take part in a trial with a 50/50 chance of receiving a placebo. With only the 10% success rate I declined; choosing instead to try to enjoy the time I had left. I was not mentally strong enough at the time to think that I may just be injecting a placebo. It was a year or two later that the offer of treatment without being on a research program was finally give; which I then accepted.

25. I would not know if other treatment should have been made available to me.

26. My infected status has impacted on my dental care. The dentist would do the check-up but then I would be required to have any work completed at GRO-B Hospital.

27. The additional person in attendance at my mother's house when GRO-B GRO-B had explained to my mother about my situation (without my consent), turned out to be the local gossip. Soon word got around the village that I had something 'like AIDS'. It was made abundantly clear to me that I was not welcome in the local pub and people would move away from me and stopped speaking to me. It quickly became clear I had to move away.

28. I have kept the HCV quiet for the rest of my adult life. I have had a difficult isolated existence. I was desperately lonely. I wanted to share my experience with people but it was necessary for me to not expose that side of my life.

29. I had spent seventeen years in complete isolation. I use to joke that I lived in a house without a number on the door or a doorbell or telephone. I certainly did not want to put anyone else at risk. I was robbed of nearly two decades of my life and robbed of the opportunity to have children. Looking back I am deeply saddened by the path my life took. Regardless of the actions that lead to my infection, poor communication and patient care compounded this into an unnecessary solitary, celibate and desperately lonely existence. Looking back, what I most remember is that, for most of my adult life, each night I would lay in bed awake and cry; fraught by the utterly empty solitude of my existence. I so longed to have children, and still do, but I now accept that is too late for me now.

30. I am sure my family suffered as well. My parents had a deeply horrible time. My family had the words 'AIDS' written across their house so I had to leave. I lived on a very small boat while I finished my college course and I then moved to GRO-B.

31. During university I had to hide the biopsies I was having. I was also fatigued so I cannot tell how much this has affected me. The hospital would get annoyed that there was no body to pick me up after my biopsy; so that they would have to keep me in overnight. I remember one doctor exclaiming in annoyance that it was unbelievable that I could not fined anyone willing to drive me home. I did not bother to explain that my complete social isolation was a conscious choose on account of the disease he was treating me for.

32. I do not know how well I would have done in my career but I have done well regardless. I made it to GRO-B at one point but I may have made it to GRO-B if there had not been so many barriers; I cannot know for sure.

33. I cannot say if there were financial affects in terms of losing money from jobs I may have been promoted to. However, I moved to GRO-B three years after clearing HCV and now I pay for every scan, check up and blood test so there are huge medical expenses here.

34. It was not until I cleared HCV that I got my life back and was able to get on with my life. I have since got married.

Section 6. Treatment/care/support

35. Other than dental care I do not think I have had any difficulties obtaining treatment. I have faced difficulties obtaining support though.

36. The only counseling I received in the UK was one 20 minute session with an unqualifies degree course councilor in my local collage. Since moving to GRO-B professional counseling has been provided to me and I now see a psychiatrist on an ongoing basis; but this was never offed in the UK.

Section 7. Financial Assistance

37. When I received the interferon treatment, the nurse told me about the Skipton Fund.

38. I have had the stage 1 payment from the Skipton Fund and monthly payments since 2008. The England Infected Blood Support Scheme (EIBSS) now pay me these payments. I received £333 a month.

39. I cannot really remember the process of the application but it was difficult in a way because I grew up in a family where you do not seek compensation, so it was emotionally confrontational to accept that I was a victim and needed to chase the money.

40. As I remember filling in the form for the payments was straightforward and I do not think there were preconditions attached to the application I made.

Section 8. Other Issues

41. Money cannot put right what has happened. Really, given the correct information at the right time, there is no reason why I could not have had a wife and family and no about of money will bring this back. Somebody should have taken the time to tell me the facts.

Anonymity, disclosure and redaction

42. I wish to remain anonymous and as I live in GRO-B I do not wish to give oral evidence.

Statement of Truth

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

GRO-B

Signed...

GRO-B

Dated: 15/02/2019