

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1502001

Exhibits: WITN1502002-3

Dated: January 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 and I live at GRO-B
GRO-B My date of birth is GRO-B I live alone in a bungalow with my dog and I am now unable to work due to ill health.

2. This statement has been prepared without the benefit of access to my full medical records.

Section 2. How Infected

3. I was diagnosed with Von Willebrand's Disease at a young age which resulted in me receiving a number of whole blood transfusions and treatment with Factor VIII between approximately 1972 to the 1990's.
4. I was infected with Hepatitis C as a result of receiving either contaminated blood transfusions or products.

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5. However, I do not know the date on which I was infected or which particular batch or transfusion caused my infection.
6. I attended the [GRO-B] Hospital and I was under the care of Dr [GRO-B] who was a Haemophilia Consultant.
7. I was provided with no advice whatsoever in relation to the risks of receiving either Factor VIII or whole blood transfusions.
8. In early 2011, I went to the doctors because I had been feeling unwell for a long time and they ran a number of tests on me which included taking bloods. Shortly after this, I was advised that some of my test results showed abnormalities in my liver function.
9. I therefore underwent further blood tests following which I was advised that I had Hepatitis C. This was in or around July 2011. **Exhibit WITN1502002** is a letter dated 22.07.2011 which confirms this diagnosis.
10. **Exhibit WITN1502003** contains extracts from my medical records dated 09.09.2011 and 26.10.2011 which confirm that my Hepatitis C was genotype 3a.
11. In or around late 2011, a Sister at the [GRO-B] Hospital gave me some advice regarding the risk of transmission of Hepatitis C and she also advised that I would have to commence treatment immediately.
12. I strongly believe that I should have been tested and told earlier that I had Hepatitis C, particularly in light of the fact that I attended the Haemophilia Centre at the [GRO-B] Hospital on a regular basis.
13. Approximately 2 years ago my consultant diagnosed me with a platelet disorder. This replaced the original Von Willebrand's Disease diagnosis and I currently receive DDAVP treatment.

Section 3. Other Infections

14. To the best of my belief, I have not been infected with any other viruses although I do not know if I have been exposed to any other viruses.

Section 4. Consent

15. As far as I am aware, I was not tested for Hepatitis C or any other viruses before 2011.

Section 5. Impact

16. Before I knew that I was infected with Hepatitis C, I always felt extremely exhausted. I cared for my elderly parents for a long time and I was a fitness fanatic; regularly attending the gym. I was so active and healthy and I could therefore never understand the incessant fatigue and exhaustion. I was such a determined person and a really hard worker in life who never complained about anything; yet I found myself in the soul destroying position of not being able to do anything to the high standard that I had so easily and routinely previously accomplished.

17. Despite my active and healthy lifestyle, I suffered from depression and low mood which gradually worsened over time. If it were not for my beloved dog I would have stayed in bed for days on end. I had absolutely no desire to get out of bed in the mornings.

18. I used to go to bed at 8pm and usually slept for a good 9 hours but always woke up completely exhausted, as if I had not slept at all. This complete and total exhaustion is very difficult to explain but I would best describe it as "*all encompassing*".

19. I found it almost impossible to motivate myself and everything felt like it was far too much effort with the result that daily life became an unbearable struggle. I received medication to treat my depression and unfortunately this

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continues to the present day as my depression has not shown any signs of abatement.

20. I used to have severe pains in the middle of my stomach and recurring headaches. My legs used to feel heavy; as though I was dragging large bricks around. I was constantly nauseous and regularly vomited which meant that I retained very few nutrients from my food and therefore lost over 2 stone in weight. I also underwent a knee replacement operation approximately 6 years ago.

21. When I was told that I had been infected with Hepatitis C, I felt dirty, ashamed and shocked. I did not want other people to know about my infection; and if anyone found out I felt like I had to defend myself and say "*I am not a druggie, I caught it from blood products.*" I was afraid to touch anybody. My whole approach to life changed and it changed how I did things. I was so worried that I had unknowingly infected my partner and it affected our relationship.

22. In relation to family and social life, my life completely changed following my Hepatitis C diagnosis. I extensively researched all of the risks and safety information about day-to-day contact with others as I felt so anxious. My family and partner knew that I had Hepatitis C. My partner was supportive and is still in my life today, and my sister, mother and father have also been supportive.

23. Aside from my partner and immediate family, I did not tell a soul about my infection as I felt ashamed and dirty. I did not want any of my friends to know about my infection for fear that they might never speak to me again.

24. Due to not telling people I managed to avoid a great deal of stigma. However, there is one incident of stigma which is, unfortunately, etched in my mind. Whilst I was employed by GRO-B I had to fill out an application form for GRO-B which necessitated the disclosure of my Hepatitis C status. Somehow, and I do not know how, this information was made public within the company and everyone was aware that I had Hepatitis C. I felt so humiliated that I ceased working for this company.

25. I commenced Interferon and Ribavirin treatment for my Hepatitis C in 2012.

This lasted for 6 months. I had to inject myself in the stomach and I also ingested tablets. It was known as the "*nasty treatment*" with particularly harsh side effects. The treatment made me feel even more exhausted and my energy levels dropped significantly; ultimately leading to the abandonment of all of the physical activities which I had previously thoroughly enjoyed. The feelings of nausea were horrific. Whilst I was on the treatment, I was caring for my elderly father which was a struggle due to the worsening of my depression, sickness and headaches.

26. If I had been advised about the serious side effects of the Hepatitis C treatment I would have never embarked upon this treatment. However, I was told that I would die if I did not commence the treatment immediately. I was put under extreme pressure and believe I was ill advised by the medical professionals.

27. Whilst undergoing the Hepatitis C treatment, I really struggled at work but I still attended. I used to work for GRO-B who I found to be a supportive and understanding company. However, I had to leave in the end because I was unable to juggle the horrific side effects of the treatment, work and family life. My father had heart failure and my mother was in a care home which exacerbated my stress levels. I had so many conflicting responsibilities at that time in my life and I must admit that it was a testament to my character that I continued to work.

28. Unfortunately, following the Hepatitis C treatment and despite my determined character, I have now had to give up work due to chronic fatigue. This saddens me and I feel like I have somehow failed even though I know that it is the system that has failed me; by giving me Hepatitis C through no fault of my own.

29. I am currently on a waiting list at the GRO-B to see whether anything can be done to alleviate my chronic fatigue.

30. I am so upset at what my life has become as I no longer recognise my pre-infection self. I loved walking, cycling and skiing. I hate feeling like this and I hate being dependent on others. Sometimes I am too poorly to walk my beloved dog and have to rely on friends in this regard.

31. I am aged GRO-B and I should still be working. I attempted to work on a part-time basis but I felt constantly out of breath which was out of my control and therefore I could not continue. I have tried so hard to continue to work but I am unable to yet I still feel bad about this.

32. Sometimes I wish I was not here anymore and I have had suicidal thoughts. However, my beloved dog keeps me going.

33. Everything has changed and my life has crumbled as a result of my infection.

34. Turning to financial matters, I confirm that I received Incapacity Benefit for 9 months during 2018. I asked my previous employer GRO-B for an early pension but they refused. I therefore appealed this decision and provided supporting evidence, in the form of medical records, and I was successful in overturning their decision. It has been a real struggle financially. My sister has been giving me £500 per month and my partner purchases all of the groceries and dog food.

Section 6. Treatment/Care/Support

35. When I was admitted to the GRO-B Hospital for a knee replacement I was marked with a "Hepatitis C" label and the medical professionals ensured that I was the last patient on the that day's list.

36. I have not been offered any psychological support following the news of my diagnosis of Hepatitis C.

Section 7. Financial Assistance

37. In 2012, a Sister at the [GRO-B] Hospital told me about the Skipton Fund and I filled out an application form seeking financial assistance.

38. The process of applying was extremely difficult, complex and long winded.

39. Initially, the Skipton Fund turned down my application in respect of the Stage 1 Payment but my consultant helped me to appeal this decision. After 12 months, I received the Stage 1 payment of £20,000 which was in or around 2013.

40. I was aware of the possibility of being able to receive grants but I did not apply because I was put off by the somewhat protracted and arduous application process.

41. In August 2017, I started to receive a top-up payment of £484 per month which was backdated to April 2017.

42. I also receive winter fuel payments of £500 per annum from the EIBSS.

Section 8. Other Issues / Conclusion

43. I would like to find out why the NHS and the Government resorted to allowing the importation of contaminated blood. I want answers and I want to know the truth.

Anonymity, disclosure and redaction

44. I would like to apply for anonymity and I do not wish 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. 22/1/2019