ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN0190/01
Exhibits: WITN0190/02
Dated: 18 March 2018

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference

I, GRO-B will say as follows: -

Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry. I live with my husband and in close proximity to my mother. I do not have any children. I am too sick to work; my mother and husband help to care for me throughout the day. I intend to explain the nature of my hepatitis C infection; how I contracted it, the treatment I received and how it has impacted my life.

How Infected

2. I was infected on 22nd May 1990 as a result of receiving numerous blood transfusion and blood products while I was in hospital with leukaemia. I received several transfusions between September 1989 and June 1990, after I had a bone marrow transplant. I was infected at GRO-B GRO-B I was only 20 months old when I was diagnosed with leukaemia and 2 and a half when I was infected with hepatitis C.

3. As a result of being so young at the time I was infected, I cannot provide details of how I was infected. However my mother remembers that before I was given the transfusions, she repeatedly asked the clinicians attending me whether the blood was safe. With all of the media attention around AIDS and HIV infections she was concerned about the safety of blood and blood products so sought assurance that they were free from infection. She was told that, "yes, the blood is completely safe these days".

4. My mum saw an article in the paper regarding litigation for my hepatitis C and consequently, I brought an action through Metcalfes Solicitors. It was Metcalfes whom informed me that the date I became infected on was 22nd May 1990.

5. I was diagnosed with hepatitis C in the summer of 1995. My mum received a letter in the post when I was 7, saying "your daughter may have contracted hepatitis C, but don't worry its not HIV or AIDS. She just needs to come for a blood test." My mum said that she didn't know how to take this.

6. I was diagnosed with hepatitis C just after I had got my big 5 years clear for leukaemia. I had gone into remission, was still having check ups, and had been given the all clear when only a few months later we got the letter about the hepatitis.

7. After we received the letter I had to go into hospital for blood tests. A couple of weeks later a doctor just phoned up my mum and said, "yes, she does have hepatitis C." The doctor wasn't our consultant but we had come into contact with him previously. The doctor did not seem that worried or concerned at all.

8. After we were told the hospital made an appointment for us to come back to have a liver biopsy. They arranged for a doctor from Kings College Hospital to do the biopsy, as they didn't have a children's heptologist at GRO-B The biopsy was done under general anaesthetic. This all happened back in autumn 1995.

9. The doctor then came back to Bristol to discuss the results with us. He said that there was mild scarring but that I shouldn't worry because cirrhosis or liver cancer would not develop for another 25 years.

10. There was a discussion of whether I should undergo interferon treatment but my scarring was not that bad and my heart was damaged from the chemotherapy I had to treat my leukaemia. Interferon treatment would therefore have been contraindicative to my heart.

11. The advice I received when I was first told about my hepatitis C infection was just that I had to be careful about sharing toothbrushes and that we had to let the school know. The school did not quite understand what it meant though. No one was horrible at the school if, for example, I had a cut or something like that but they just didn't understand. My mum also remembers being told that hepatitis C could be transmitted sexually as well.

Other Infections

12. I have not received any infections other than the hepatitis C as a result of being given infected blood and blood product

Consent

13. I do not believe that I have been treated or tested without my knowledge or consent.

Impact

14. My hepatitis C had quite a significant impact on me growing up. Due to my infection I often felt fatigued. I actually made a statement of how I was feeling after being infected in 2001 as part of legal action with Metcalfes Solicitors. This is exhibited as **WITN0190-002.**

15. I really struggled at secondary school as a result of my constant fatigue. I was always slower than other children and tired much faster. As a result I struggled to make friends and also with my schoolwork. Other kids would do things like go out shopping and generally socialise with each other. I couldn't do this, as I would just tire too easily. It had a knock on effect and I struggled to talk to people as well. Eventually, my continued fatigue meant that I had to be home tutored.

16. This was made worse by the fact that it just felt like no one believed me when I explained how tired I was all the time. Medical professionals would say to me, "you shouldn't be feeling like this yet, it is too soon." It was the tone with which they would say this which showed their disbelief. It was as if they were saying your wrong you can't be feeling like that.

17. I went to see a psychologist, as I was depressed. I didn't have any friends, I couldn't cope with school and it seemed that not even the psychologist believed me when I told her how I was feeling.

18. The difficulty with assessing the full impact of the hepatitis C is that at the same time I was still dealing with the side effects of my leukaemia and chemotherapy. By the time I was 14 years old my heart was getting worse and that could have contributed to the fatigue. When I was 15 I suffered from heart failure which resulted in me having a heart transplant by the time I was 16. The drugs I had to have for the heart transplant (immunosuppressant) were also damaging and so it's hard to know how much damage was caused by the hepatitis and how much by my heart transplant.

19. There was also the chance that the immunosuppressant would make my hepatitis worse so there was a big meeting to make sure that proceeding with the heart transplant was the best option. I had the transplant at Great Ormond Street Hospital.

20. After my transplant I eventually returned to Bristol from London and went back to my schooling. I was able to take 5 GSCEs when I returned. After my GCSEs I enrolled on a child care course at college.

21. Unfortunately, the journey to get to college required me to get on 2 buses and travel for about an hour. I would not have been able to cope with this amount of travel on public transport so I had to rely on my church friends to take me.

22. I wanted to go on and do the next level of childcare at college but this involved longer days whereas the initial course I took was only part time. It would have been too much of a struggle to attend full-time so instead I moved to a closer college and did a health and social care course. Again, my church friends had to help and give me lifts to my new college. However, my condition deteriorated as a result of my exhaustion. I was suffering the entire time.

23. In March 2007, when I became an adult I was treated by a new doctor, Dr Gordon. Dr Gordon was my hepatitis C adult specialist at the BRI in Bristol. Dr Gordon was excellent and I finally felt like I was being treated properly by someone who understood and believed what I was feeling.

24. At this point I had a liver biopsy, which showed some scarring. By the time I had my next biopsy in 2011 I had developed cirrhosis. However, I could not be treated with interferon due to the complications I had with my heart and kidneys.

25. Finally, in 2012 a new treatment came out which still included interferon but it was given together with ribavirin and a new drug, boceprevir. I was given steroids to try and protect my heart.

26. Physically, the treatment made me really sick. I remember I had to call my mum one morning because I was in a heap on the floor of my room. I couldn't keep anything down at all. This started within 3 months of beginning the treatment.

27. My mum administered the interferon injection for me. I also had to take 8 boceprevir capsules, 4 times a day, on top of all the other medication I was already on. I had blood tests regularly to check the levels of my heart.

28. I have never recovered from the hepatitis C treatment. It affects everything: my concentration, my eating habits, and my weight. After my heart transplant I weighed 6 and a half stone but after the treatment I could barely make 6 stone.

29. In terms of my concentration, I used to like reading books but now I struggle to read the words off the page. I used to be able to read a couple of chapters but now I can only read a page. I have the same problem with watching TV and using computers - I can only use them for a limited time.

30. The problems I referred to with exhaustion persist as well. I have no energy and it just makes everything difficult.

31. The first round of treatment I had was unsuccessful. In January 2015 I was given a 12-week course of sofosbuvir and ledipasvir with ribavirin, as Dr Gordon knew how much I was struggling - as soon as Dr Gordon could get her hands on these drugs for me, she did. At this point I was 28 years old.

32. Since the 12-week course of sofosbuvir, ledipasvir and ribavirin my hepatitis C is undetectable. There were a couple of nodule things that were found in my liver, but both were really small and is something the hospital will check up on and make sure they don't grow. It is hepatocellular.

33. Although I am cleared now, everything remains a struggle. I suffer with a lot of fatigue. My doctors believe that because of the immunosuppressant, I have low immunoglobulin. My anti-bodies are just not working properly. The treatment for this would be an Immunoglobulin (anti body) Infusion, one or twice a month for the rest of my life.

34. I will have to go have more transfusions at South Meads Hospital to combat my low immunoglobulin. My key concern is the uncertainty of it all and that I could be at risk of infection from the immunoglobulin infusions, which are taken from blood products. It is always a worry as we were told that the blood was safe when she I was infected with hepatitis C. In one of the letters I received from the hospital about the transfusions I am to have it still says there is always a risk of infection when receiving a transfusion.

35. My husband knows how ill I was after the first round of treatment for hepatitis C and he worries because he doesn't want me to be like that again. We've been married for 6 years and he helps look after me along with my mum. My poor health has an impact on him; he can get quite low as he worries about me.

36. Now with the exhaustion I can sometimes manage a whole day of work but sometimes I have to sleep throughout the day. Usually I have my sleeps in the afternoon. I do struggle with sleep but I think that's down to the tablets that I have to take. It really depends on the day.

37. One of the knock on effects of my hepatitis was on my family. For example my brother, who is 5 years younger than me, was really struggling as he was growing up because of the all the attention I got, he felt neglected.

38. In terms of stigma, I remember I once went in to hospital for something to do with my kidneys and I had to have blood tests every few hours. One of the nurses got a bit funny with me when there was a blood spillage. I was about 19 or 20 years old at the time

39. Additionally, I once I applied for a job at a B&Q cafe after I finished school, and I wrote down that I had hepatitis C and because of that they couldn't hire me.

Treatment/Care/Support

40. The difficulty I had obtaining treatment for my hepatitis was due to the complications that resulted from my leukaemia. Despite my biopsy in 2007 showing scarring Dr Gordon had deemed it too risky to give me interferon treatment due to the complications with my heart and kidneys and the immunosuppressant I was taking.

41. The same was said after my second biopsy in 2011 despite it showing that I had cirrhosis. Again, Dr Gordon said it was just too risky and not safe for me. She did keep reassuring us that there were new treatments on the horizon though. I had to wait until2012 when the new treatment which involved interferon together with ribavirin and boceprevir was available before I was able to have treatment

42. I needed more support when I was a child. When I became an adult it was fine but I really needed more support when I was younger. I needed someone to tell me it was ok to be so tired and ok to feel the way I was. My mum said that she just used to dread me going to school, as she knew how much I was struggling.

Financial Assistance

43. My mum saw an advert in the paper advertising the hepatitis C litigation in 2001. From this I received a payment of £20,000 from Metcalfes solicitors.

44. That money was put in a trust and I used some of it later to buy myself a laptop. I was then notified that I would also get payments form the Skipton Fund by the Department of Health. On 26th January 2004 I received a letter explaining how to sign up and setting out the eligibility requirements. It advises you to apply using a medical form and following up with evidence. This letter was following on from a press release given by the Department of Health on 23rd January 2004.

45. Then on 20th February 2004 I got a letter from Metcalfes Solicitors in regards to the Department of Health press release outlining ex-gratia payment scheme. The letter had a phone number to contact for details of how to claim or a DH email address. This lead to me receiving £20,000.

46. When I got cirrhosis, Dr Gordon assisted me in getting more funding and so I got another lump sum payment of £50,000. This money came from the Skipton fund.

47. I still receive financial support from the Skipton Fund. I receive £1500 every month. I also get disability benefits as I'm not able to work.

48. I struggle financially. I don't know what would happen if rent was to go up, because of my condition and the fact that I am unemployed, I am unable to get a mortgage.

Other Issues

49. Contracting and suffering from hepatitis C was just "another thing" that I could have done without having. In addition to the leukaemia and all the problems and side effects I suffered I also had to deal with the symptoms of hepatitis C and I still suffer from the side effects even now. It was all just another worry; all the other illnesses, treatments and drugs that I had to take that affected my hepatitis C and visa versa.

50. My mum remembers being upset after I had my heart transplant as the doctor told her that I wouldn't be able to have another transplant (as some people do) due to the hepatitis C. This meant that there is nothing they would do if I had any complications. He had no right to say this, as he wasn't a liver or heart specialist. They way he said it to my mum just depressed her so much and she had to go onto antidepressants after that.

51. Psychologically speaking, being infected with Hepatitis C has badly it effected both my mum and me.

Statement of Truth

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

Signed **GRO-B**

Dated 18.03.2018