

Witness Name: [GRO-B]

Statement No.: WITN0390001

Exhibits: Nil

Dated: 17 January 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF [GRO-B]

[GRO-B]

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6 November 2018.

I, [GRO-B] will say as follows: -

Section 1. Introduction

1. My name is [GRO-B] My date of birth and address are known to the Inquiry. I am married with two children, aged 11 and 13 and I work part-time as a Teacher's Aide.
2. I intend to speak about my infection with Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life.

Section 2. How Infected

3. I was infected with Hepatitis C through my mother who received blood transfusions before she became pregnant with me.

4. My mother received blood transfusions following the birth of my older sister in 1966 and myself approximately 5 years later in 1971, at GRO-B
GRO-B now known as GRO-B Hospital.
5. My mother needed the blood transfusion because she had lost lots of blood during both her labours. Whilst my mother was pregnant with me she was also losing lots of weight, couldn't hold food down and, in general, was quite weak. I am not sure how much blood was given to her.
6. My mother has a limited understanding of the English language and is unsure if she was told of the risks associated with receiving a blood transfusion. My father who had a better understanding of the English language was not present at the birth of my sister or me, as he was working. Therefore, she did not have anyone to help explain what was happening during her time at the hospital.
7. Based on what I have been told, I contracted Hepatitis C through the blood transfusion my mother received after the birth of my older sister. I confirm that I have never shared a needle or gotten a tattoo. I am not sure if I received a blood transfusion when I was born. But I doubt it since I was born at 9 months and I was a normal weight.
8. My mother and I both have been diagnosed with Hepatitis C Genotype 1B.

Hepatitis C Diagnosis

9. My mother was holidaying in Italy when she was diagnosed with Hepatitis C, this was on 20 May 1997; her diagnosis was confirmed through a blood test when she tested positive for HCV. She went back to the UK and her diagnosis was confirmed through another test.
10. Our family GP advised the whole family to get a blood test after finding out about my mother's diagnosis; this was approximately around 2000, or

ANONYMOUS

2001. I remember I was in my late twenties when I was tested. I don't understand why there was a delay in suggesting my family be tested or why there was a delay in informing the general public.

11. After my test, I went back to my GP's surgery and was informed of my Hepatitis C diagnosis. I remember that I was in shock and I didn't know what to do, my sister who was with me started crying. I do not remember my GP giving me a thorough explanation of Hepatitis C or how to manage the infection but he said that there was treatment available. I also remember him telling me to make sure I didn't touch anyone with my blood, I don't remember much else.

12. I was referred by my GP to Dr Dusheiko, who at the time was the Head of Hepatology at the Royal Free London for treatment. He advised me to have a liver biopsy to assess how much of my liver was affected as I had been living with Hepatitis C all my life. I had my liver biopsy on 15 April 2003.

13. Following my biopsy, I went back for a second appointment with my Consultant and I was told that I had mild chronic Hepatitis C, with minimal portal fibrosis. They said that even though I had it, luckily it was not bad.

14. I was asked about my diet and lifestyle, I confirmed that I never really drunk alcohol, nor did I smoke. The doctor said that because of my healthy lifestyle my liver hadn't been as affected. Since my diagnosis I have always been cautious of my alcohol consumption, watched what I ate including avoiding fried food.

15. At the hospital, I was given a leaflet, which provided information about the Hepatitis C virus and about the risks of infecting others.

16. My general observations about finding out about my diagnosis is that I should have been told sooner and my mother should have been diagnosed sooner. I hate the fact that I have had this all my life and I am angry that I

have contracted this disease. I am worried that I don't know how long I could live with it without flaring up, and when I was pregnant I was worried about passing it on to my kids. Whilst I was pregnant I made sure all the medical staff knew that I had Hepatitis C and I was quite meticulous about my birth plans.

17. I still get upset about my diagnosis, I have been careful all my life and haven't done anything to warrant contracting it, like taking intravenous drugs. I want to be around for my children, in good health, not with a bad liver.

Section 3. Other Infections

18. Aside from being infected with Hepatitis C, I am not aware of receiving any other infection as a result of being given infected blood or blood products.

Section 4. Consent

19. I can confirm that I gave my consent when I was tested for Hepatitis C.

20. Additionally, I consented to the treatment I received which was also fully explained to me. I understood what the treatment was and the side effects associated with the treatment.

21. I am not aware of any non-consensual tests or treatment.

Section 5. Impact

Impact of the Hepatitis C virus: mental and physical effects

22. When I was first diagnosed with Hepatitis C I was shocked, numb and scared; it took me a while to digest what I had been told. My diagnosis

affected my mind because I did not fully comprehend what Hepatitis C was. It was not until I went to the Royal Free Hospital that I started to understand.

23. This diagnosis still affects me every day, however, I try not to think about it. I feel like it is something lurking in the shadows and I don't know if it will appear again, even though I have had treatment. I don't want my children to know or worry about it, they are both young and they don't need to know these things. I just hope that they are not affected.

24. It also upsets me that I cannot give blood, as they obviously wouldn't accept me as a donor.

Impact: further medical complications

25. Throughout my life, I have had numerous health problems including irregular periods, fatigue, mood swings and low iron levels. I have been diagnosed with thalassemia and prolactinoma.

26. I am unsure if these health issues are a result of my infection with Hepatitis C; however in comparison, my older sister has never had any major health issues.

Impact: treatment

27. I started treatment in February 2013 at the Royal Free Hospital under the care of Dr Dusheiko and Dr Jude Oben. I regularly saw a Clinical Nurse Specialist, Theresa Moore - she is a lovely lady who also treated my mother.

28. There were various treatments that my doctors at the Royal Free Hospital informed me about.

29. I decided to go on a 48-week blood therapy course, which was a triple treatment made up of Viraferon Peg pen 80 mcg, Rebetol 400mg twice a day and Telaprevir 1 125 mg twice a day.
30. I was told that the treatment would make me feel unwell and could cause various side effects. I knew what to expect due to my mother's Hepatitis C treatment experience, which made her very weak to the point of hospitalisation; I was to undergo similar treatment but with an additional tablet which was very strong.
31. My Nurse, Theresa Moore helped me through the treatment, I remember she told me that I would have to try and counteract the side effects and advised eating foods with high fat contents like cheese and yoghurt.
32. Twelve weeks into my treatment, I had to have two blood transfusions in April and May 2013 as I suffered from extreme anaemia causing me to feel weak and constantly fatigued.
33. I suffered severe weight loss from the treatment and got down to about 42-43 kilograms. Additionally, I suffered from heart palpitations and mood swings; I had no energy and had to force food down because I couldn't eat much. I suffered from hair loss and had a rash on my neck and upper body.
34. During my treatment time, I felt depressed and told my husband that I wanted to kill myself. Although my father had passed away a few years earlier, I was also still grieving my father's death which made handling the effects of treatment more difficult. I did not seek medical attention at the time nor have I been diagnosed with depression. However, at times I do think I should have sought medical attention, following diagnosis and during my treatment.

35. I do not remember being offered counselling, but I do not think I would take it because of the stigma at the time regarding both counselling and Hepatitis C. My way of coping was driving to Tesco on my own and crying in the carpark, just to let it out.
36. I do recall arguing with my husband as at times the diagnosis and treatment were too much for us. I do still feel depressed at times but maybe this isn't about my diagnosis, could just be life in general.
37. I had no motivation to do anything and couldn't get out of bed. I felt guilty for not being able to look after my children. During this time, my husband and I hired a child minder to assist us in our everyday lives as we did not have a large family support - my husband's mother and my father had both passed away a few years earlier and both our surviving parents are elderly.
38. During treatment a white patch appeared on my face, next to my mouth/chin; I still have this patch on my face. At the time, I was referred to a Dermatologist at the Royal Free Hospital and I remember I was asked whether there was a family history of skin colour discolouration; there is no such family history. There is an inconclusive result about where the patch came from. I know that it first appeared during my Hepatitis C treatment and has remained since then. During my day to day life, I make sure to cover the patch using makeup and I know to be very careful in the sun.
39. Following treatment I completed the obligatory tests. I was told that I was clear of Hepatitis C but that it will always lie dormant within my body. I was told that I was more than likely to be fine, but there was no guarantee made.

Impact: other treatment, medical and/or dental care

40. Fortunately I haven't had any major dental issues but I have disclosed my Hepatitis C status to my dentist. There was no issue or problems following my disclosure, it was taken on board and they are cautious.
41. I do think it should be law that you need to disclose your status when undertaking activities that could draw blood, for example, when I get my eyebrows done there is potential to draw blood and I don't want to be responsible for infecting anybody.

Impact on my private, family and social life

42. My sister was with me when I received my diagnosis and she started crying immediately. When I told my mother, she became very upset and blamed herself for my diagnosis as she felt that it was her fault for passing it onto me. Both my mother and sister were worried about me throughout my treatment as they saw me losing weight and hair.
43. At the time of diagnosis, I was scared and worried to tell my boyfriend, my now husband. I was worried about my ability to have children as I always wanted to start a family. I remember I was in the car when I told my husband, who at the time was also dealing with his mother's cancer diagnosis. At first he was upset, questioning why these things happened to those he loved. However, he was completely supportive and started researching the disease.
44. I have not told my children about my Hepatitis C but I had them tested when they both turned one year old. Since we had them tested, my husband and I carried out further research and found that it is best to wait a bit longer than 12 months before testing whether a child has contracted Hepatitis C, so I think we may have tested them too early. This is another worry of mine, which plays on my mind. I am very careful with them and I make sure that they are never in contact with my blood.

45. When I was receiving treatment they were approximately four and seven years of age and could see I was unwell; my husband tells me that they continuously asked if I was ok.
46. I do not have a large family network in the UK, my relatives are mainly in Italy. They know that my mother and I both have been diagnosed with Hepatitis C and following disclosure, they view it as an unfortunate incident that has happened. They understand it was out of both our control.
47. I have only told a select few close friends about my diagnosis but they don't know anything about Hepatitis C. Most of them only remember stories of people contracting it and then dying. I have made jokes out of the diagnosis saying things like "You won't get it if we share towels or use the same items" but of course I am very careful if I cut myself on something, I will always bandage and cover up the wound.
48. My friends have been very understanding and supportive, especially whilst I was undergoing treatment. My husband told me that they would drop by with food for the family because they knew I was too weak to get out of bed and cook. When I did manage to see them, they saw I was quite skeletal-looking having lost so much weight, and they worried about me.
49. I did notice that one friend wasn't as understanding or supportive and distanced herself suddenly following me disclosing my diagnosis. I did try and reach out a few times after; however, we are no longer friends. I think this is to do with the lack of information and people being ignorant.

Impact on education/work/finance

50. My diagnosis did not impact my education, I was in my late twenties and had completed my education.

51. With regards to work, I never mentioned it to any of my colleagues. I wasn't working at the time I undertook my treatment as I had been taking care of my children up to that point. However, I always intended to stay at home to look after my children until they went to school, instead I undertook my treatment. Following my treatment and recovery, I sought employment, this was on a part time basis as I didn't have the energy to work long hours.

52. Financially, my family was impacted as my husband was out of work whilst I was undergoing treatment as he had to care for me. Additionally, whilst I was undergoing treatment we had to hire a child minder to assist in looking after the children. This was an added financial burden seeing as though neither my husband nor I were working; however, it was a necessary expense.

Section 6. Treatment/Care/Support

53. I confirm that I did not face any difficulty accessing treatment for Hepatitis C. In fact, I was able to delay treatment until my youngest child was at school full time.

54. My experience at Royal Free Hospital was very good. The hospital gave me lots of information, including leaflets to take home, about Hepatitis C and I was informed about the ways that I could infect people. I was also advised to be vaccinated against Hepatitis A and Hepatitis B, which I did do. The hospital answered any and all the questions I had, but it was only when I went to the Royal Free Hospital that any questions were answered as my GP did not provide me with information.

55. About a year ago I went to see my GP in order to get another test for Hepatitis C but I was told that they don't do tests for it now. It was explained to me that tests are carried out for specific markers and should those markers be off, then a test for Hepatitis C would be carried out. I am

not sure why the Hepatitis C test is not carried out, perhaps this is to do with the costs associated with the tests. I took the test for markers and the only result was a lack of vitamin D and low iron levels.

56. I do not remember being offered counselling after my diagnosis and during treatment, but I do not think I would take it because of the stigma at the time regarding both counselling and Hepatitis C.

Section 7. Financial Assistance

57. Through my husband's constant research, he made me aware of the Skipton Fund that was available to people with Hepatitis C. I remember after I signed up to the fund and I received a form where I wrote details about my diagnosis, treatment and the doctors who treated me. I cannot remember if I needed to provide supporting documentation or confirmation from any of my treating medical professionals. I do remember having to explain that my mother received a blood transfusion and that I, in turn, was infected.

58. The Skipton Fund paid me £20,000.00 which was confirmed via post sometime in the late 2000s.

59. I do not recall agreeing to any pre-conditions before I received the payment. I do recall that there was an additional payment but I am unsure what this was as I was not in receipt of this.

60. Through the Skipton Fund I was informed of the England Infected Blood Support Scheme, this was not long after I received the lump sum payment of £20,000.00.

61. I had to complete application forms but I do not recall if I had to provide any supporting documentation. I do not recall the process for the England Infected Blood Support Scheme being difficult. I confirm that I am in receipt

of monthly payments of £333.00 from the England Infected Blood Support Scheme.

62. I did apply for additional supporting payments from the England Infected Blood Support Scheme, however I was ineligible for this payment. Apparently, I am not sick enough to receive more payment although it is something that has affected me all my life and will continue to.

63. I am annoyed that there has been no financial assistance made to people who have had Hepatitis C from birth. I do think it affects me in terms of my mood, energy levels, how I approach situations and my outlook on life.

Section 8. Other Issues

64. I had two particular observations, which I wished to share. I believe that something needs to be done about all this; a huge amount of people have been affected and it will affect people for a long time. In addition, someone or some organisation needs to be held accountable; this has given a lot of people a life sentence.

Statement of Truth

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

Signed

GRO-B

Dated 01-02-2019.