Infected Blood Inquiry

18 FEB 2019

Witness Name: GRO-B
Statement No.:WITN0242001
Exhibits: None
Dated:

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 07 December 2018.

I GRO-B will say as follows: -

1. Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry. I moved to this country from Northern Spain when I was in my teens. I am now divorced. I have a son who is grown up and lives away from home as well as grandchildren. My daughter passed away in GRO-B 2011.

2. I intend to speak about my blood transfusion and subsequent Hepatitis C infection. In particular, the nature of my illness, how the illness affected

me, the treatment I received and the impact it had on me, my family and my life.

3. I have been asked if I have legal representation and the answer is no.

2. How Infected

4. I gave birth to my second child, a son, on GRO-B 1974 in Greenwich Hospital, now known as Lewisham Hospital. I was 21 years old. I had difficulties at birth and required a blood transfusion as a result. I was given the transfusion and within 24 - 48 hours I became so ill that I had to be isolated from my newborn son and ended up staying in hospital for a month. I had mouth ulcers and a fever. I had to leave my young daughter in the care of my parents-in-law. I wasn't getting any better, and the doctors didn't know what was wrong so ultimately I discharged myself in order to leave. At the time of the transfusion I was given no information about potential risks or adverse effects.

5. Although I still felt unwell when I discharged myself from hospital I told myself that I had to get on with life as I now had two children that I needed to care for and look after. I didn't think anything of it at the time, but this time in hospital marked the beginning of my constant physical struggle. Throughout the following years of my life I struggled constantly with regular bouts of flu which I found extremely debilitating. I used to joke that it was my special flu, as I would get sick when no-one around me was sick so there was no-one I could have caught it from.

6. It was very frustrating to constantly feel so unwell without being able to pinpoint why. I continued to suffer in this way until my late 30s, when my physical condition became significantly worse. I began suffering from extremely bad stomach cramps and I lost a lot of weight due to vomiting and diarrhoea. I went to my GP several times to try and find out what was wrong. I was asked if I had been to North Africa or been eating goats cheese. I was prescribed medication but it didn't help.

7. My children always asked what was wrong with me because from the outside I looked so healthy. I didn't drink and smoke so I helped myself that way but I was always ill.

8. When I was 54 years old I developed an abscess, it made me very ill and further affected my digestive system. I was unable to eat and I was often forced to take long breaks in the day to lie down as I had no energy and felt so unwell. I was forced to go to A&E in order to have the abscess taken out. I was put on a course of antibiotics afterwards.

9. In and around 2005 and 2006 my medical issues became recurrent. My abscess kept returning and I kept being put on antibiotics. It was thought for a while that I was suffering from Lyme disease. Every time I went to the hospital I had a blood test but I was never tested for hepatitis. My medical records were never consulted so the blood transfusion I had had in the 1970s was never considered and my hepatitis C remained undetected for the majority of my life.

10. My digestive problems were such that I regularly visited the gastroenteritis department at hospitals. It was decided that I should be put on a course of steroids. In order to be prescribed the steroids I had to have a blood test which tested my liver function. This proved to be the turning point. The gastroenteritis department wrote to my GP who subsequently told me over the phone about my diagnosis of Type 1 Hepatitis C in late October 2012 when I was 61 years old.

11. During the phone call when I was told about my hepatitis C, my GP gave me some information about the risks to others and measures to take to avoid this, but I was in no way made aware during that conversation of just how ill I was. Neither was I at any point asked to come in to see my GP to discuss in further detail what the next steps were. All the information I was given was over the phone during that conversation when I was diagnosed. I feel that this was shockingly insufficient, I was never given support during

this extremely difficult time and there is a lot of room for improvement within the health system in this regard.

12. It was an absolutely shocking revelation. Immediately after my diagnosis my liver was scanned and my physical condition turned out to be much worse than I had ever imagined. I thought I was dying and didn't know how long I would live. To make matters worse, I was told about this life-changing diagnosis less than a year after the death of my daughter. I was a mother, grieving the death of my firstborn and only daughter and was told out of the blue that I had been unknowingly living with Hepatitis C for 50 years.

13. I was trying to process the death of my daughter and I was forced to put everything on hold to confront the battle against this disease, which now lay ahead of me. I didn't want to tell my son about my diagnosis as we had so recently lost his sister.

14. Finding out about hepatitis C at the age of 61 having been suffering with it for so long has been very difficult for me. It bought back a lot of bad memories as I have struggled for so many years never knowing why.

3. Other Infections

15. As far as I am aware the only infection I have had as a result of being given contaminated blood is Hepatitis C. I feel lucky in this regard that I didn't contract anything else.

4. Consent

16. I gave my consent for the HCV test and I am not aware of any additional tests being conduct for any other purpose.

5. Impact

17. The debilitating effects of the illness have affected me my whole life. I had been a bright and ambitious young woman. I had come over to this country when I was in my teens from Spain and I had always loved languages. I wanted to gain a degree in English Literature. I was offered a place at a college in Oxford when I was younger but due to the effects of the blood transfusion when I was 21 I was forced to prioritise some things in my life over others.

18. Throughout my life it has always felt like every time I tried to do something I would try it for a few months but I would never have the energy to see it through.

19. I have been forced to prioritise what I had to do in my career and balance this with the needs of my children. Hepatitis C has ensured that I am not the woman I could have been. I have always tried to get on with life as best I could and put my ambitions and desire on the back burner.

20. When I started to hear about the scandal with blood transfusions and blood products I never thought I would be one of those affected by it. I always thought that my illnesses were my fault because I wasn't looking after myself properly. It has been absolutely devastating for my family, especially my son and me. He feels responsible because I needed the transfusion when he was born. He has had to bear the impact of my disease.

21. After my diagnosis I went to the hospital to see a nurse and a doctor that specialised in internal medicine. I was told that my treatment would start in February 2013. I waited patiently, still not knowing if I would live through the treatment only to find out that once February came around, my case and paperwork had somehow been overlooked and lost in the system. No one got in touch with me to inform me that my treatment would start and I

was forced to make an appointment at the hospital and follow it up myself. Because of this I was unable to start my treatment until May 2013.

22. It was at this point that I decided that I had to share the news of my diagnosis. I had to share what I was going through with my friends and family and it was nightmare. I didn't really know anything about hepatitis C as no-one had sat down and told me about it so I had to do my own research. Through this I realised that it wasn't something you could just take a prescription pill for.

23. The treatment took a heavy on toll on me, I feel fortunate that I have always looked after myself by eating a balanced diet, never smoking and never really drinking. I think this helped me deal with the treatment but there were many times that I felt I would have died if I hadn't taken care of myself so well.

24. In May 2013 I was put on a six-month treatment course of Interferon which finished in October 2013. I had Interferon once a week but I had a reaction and it made me very ill. I had to have a blood test every week. I also had to take Ribarivin which made me anaemic. In September 2013 I was told by the hospital that I needed to have my second blood transfusion in my life because I was so ill due to the treatment. I kept being told that I had to finish my treatment but it made me so ill and it was absolutely terrible.

25. I then had to wait another six months to find out if I was clear of hepatitis C. I went through hell only to find out that the treatment hadn't worked and I was still positive.

26. In many ways finding out I still had Hepatitis C even after treatment was even worse than finding out the first time. Because I had already been through it all once, I knew what I had to go through again. I still didn't know if I was going to live or die or get liver cancer.

27. Throughout this experience I felt like I was treated as though I had very little intelligence. Although it was offered to me I never had any counselling or emotional/ psychological support of any kind as I am not a depressive person and always try to make the best out of a situation, but this was not made easier by the way I was treated by medical staff throughout some of the hardest years of my life.

28. I'm upset because of what I've had to go through in the past few years. When I wanted to grieve for my daughter I faced a serious illness. I was forced to grieve after my treatment, as I didn't want my son to lose his mother as well as his sister so I had to focus all my energy on the treatment.

29. After my first course of treatment I had to allow my body to recover before I could begin another round. I researched different types of treatment to Interferon considering the reaction I had to it. A test type of my genes was conducted and it revealed that Interferon is essentially like poison to my genes and I had gone through six months of it.

30. I chose Harvoni for my second round of treatment. I had to wait for it to be approved in the UK. I also required the approval of every department of the NHS in Scotland to be given this drug. They could see from my medical records that I had always looked after myself and they had to make a decision as to whether or not I was worth spending the money on. In my eyes I was saving them money by not having a liver transplant or taking up a lot of time in hospital.

31. It was finally approved and I made sure that I became a priority to begin the course of treatment. I was the second person to ever go on a course of Harvoni in the United Kingdom.

32. The course of Harvoni lasted three months, it still made me poorly and I had to take Ribarivin alongside it which made me anaemic again but this round of treatment was definitely better than the Interferon. I had to wait

another three months to find out the results of the treatment and was finally told that I was clear of Hepatitis C.

33. I don't think I will ever fully recover from the effects of the two courses of treatment, there are times when I still feel like I am going through it all but I have to keep moving forward for the sake of those around me.

34. I still have bad days, I still get colds very easily, it feels to me as though my whole immune system has been compromised. I don't have the energy I should and I have read that Hepatitis C can give those infected with it digestive problems. I suffer from Crohn's disease and still have contact with gastroenterology departments now. All I can do now is take as good a care as possible of myself and take each day as it comes.

35. I still feel like I can't openly talk about what I've been through, there is so much stigma and taboo surrounding the topic and I don't want others getting the wrong idea about my past.

36. Contracting Hepatitis C from a blood transfusion when I was 21 years old has impacted my whole entire life. I have been forced to work on and off throughout my life, depending on my condition. My son feels financially deprived because of this. It affected my relationships with my son and my ex-husband and I now feel like I haven't been able to fulfil their expectations because I was always such an outgoing person and have been forced to hold back from so much throughout my life.

37. Everyday I feel the loss in myself of the life I could have had. If I had gone to a private hospital to give birth to my son I would have had a clean blood transfusion. To me that is a criminal offence.

38. I have a regular lifestyle and I have always been careful to manage myself well even when I've been at my most ill, but I will always feel as though my dignity has been stripped away from me.

6. Treatment/Care/Support

39. Whilst I was completing the course of Interferon tests were done on me to check whether or not I was displaying symptoms of mental health disorders.

40. Although counselling and emotional support were offered to me, I didn't want to take them up as I was going through a very personal grieving process at the same time but I felt like I had to dedicate all my energy and attention towards myself and getting through the treatments and getting better.

41. I found the support of my GP at the time of my initial diagnosis to be very poor. I was told about a life-changing disease with no prior warning or preparation over the phone. I have never felt like enough information or support was provided to me at the time of my diagnosis and it is extremely disappointing.

42. However I still see and rely on that GP/ Practice to this day and so I feel limited in the action I am willing and able to take.

7. Financial Assistance

43. In 2013 the hospital filled out the application form for me for the Skipton Trust Fund and after I finished my first course of treatment in October 2013 I received a payment of £21,000.00.

44. I also get a monthly payment from ESS, though to my knowledge the Skipton Fund manages all this. I also receive monthly payments from the Skipton Fund as well.

45. I have found the Skipton Fund very helpful and I didn't find the process of applying for financial assistance particularly difficult because the hospital helped me.

46. I had to provide copies of bank statements in order to prove that I qualified but once this was confirmed I have had no difficulties with the payments.

8. Other Issues

47. I wanted to talk about my experience in this statement not for myself but for all the women like me that went to have a baby and then ended up in my situation. I want my voice to be heard because you hear so little about women like me who had gone into hospital full of hope to have our babies when we were young and have had to suffer ever since. I couldn't live with myself if I didn't share my story because of this.

Statement of Truth

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

Signed **GRO-B**

Dated 16 - February 2019