ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN7600001
Exhibits:
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 14 December 2022.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1947 and my address is known to the Inquiry.

2. I am divorced and have two adult daughters from my first marriage and two grandchildren. One of my daughters now lives in The Philippines.

3. I intend to speak about my infection with Hepatitis C ("HCV"). In particular, the nature of my illness, how it has affected me, the treatment I have received and its impact on my family and our lives together.

4. I confirm that I am not legally represented, and I am happy for the Inquiry Team to assist with my statement. I wish to provide my account anonymously for personal reasons.

5. The Inquiry Investigator has also explained the Inquiry's statement of approach and 'Right to Reply' procedure. I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

Section 2. How Infected

6. I was born in Cairo, Egypt, in 1947 and first travelled to the UK when I was two years old. My grandmother was GRO-C and after the Nasser government forced out the Europeans from Egypt, I officially moved to the UK in 1956 and was raised in GRO-B Sussex.

7. My first husband was GRO-C and we began living together in Rome in the 1970s before we got married. Our first daughter GRO-B GRO-B was born on GRO-B 1976, GRO-B in a private wing at GRO-B Hospital in GRO-B

8. I contracted an infection during the delivery, which was not pleasant, but other than that, I was fine and did not require a blood transfusion.

9. My second daughter, GRO-B was born via caesarean section on GRO-B GRO-B 1977. Before the delivery, Dr GRO-B at the GRO-B GRO-B a private hospital on GRO-B had advised that as labour had been challenging with my first child and that the best way to deliver this baby was through a caesarean section. I agreed, and we scheduled the operation for tea time on GRO-B

10. After the delivery, I was informed I had been given four pints of blood. I cannot remember why but I assume this was due to blood loss. I

trusted the doctors, and it was one of those instances where I was grateful to be alive, and my baby was healthy.

11. No one ever warned me about any potential risks associated with receiving blood or a blood transfusion. In hindsight, if they had been aware of such risks, they should have informed me.

12. I remained at the hospital for a few days before I was discharged to return home, to GRO-B in GRO-B London GRO-B

13. Life carried on as normal after my recovery. If I ever felt tired, I put it down to being a busy mum raising two children under two years old full time. I only noticed that I was very slim compared to my friends and could not put on weight however hard I tried.

14. My mum was a typical GRO-C woman of her time and did not believe in complaining, so even if I felt unwell, I was compelled to just get on with things.

15. My marriage broke down about five years later, but my dad stepped in to help. He suggested we move to New Zealand, where he was, at the time, running his businesses. He owned various properties and was building a yacht club in the GRO-B of Auckland. My children and I lived in New Zealand for about six years.

16. In 1993 or 1994, the children and I moved to Hong Kong with my soon to be second husband, GRO-B He seemed sensible and was very persuasive about looking after us. We lived in Hong Kong for three years, and by this time, I had begun to experience some symptoms of HCV.

17. In Hong Kong, my ill health became more noticeable. GRO-B was a very sociable person and attended and hosted a lot of parties. I found it

difficult to tolerate wine, and I also experienced reactions to various kinds of food.

18. If I had one glass of wine, I would experience a terrible headache in the morning. I had a bloated stomach after almost everything I ate, so I decided to try a more holistic diet. All I could eat was bland food, no fat, no milk, or yoghurt. I believe it is related to my gallbladder, as I cannot eat any fatty substances.

19. I developed osteoporosis and suffered from terrible itchiness, joint pains, lethargy, and extreme fatigue. My shins and my chest were particularly itchy.

20. I also went to the doctors constantly, but people said I was being precious and there was nothing wrong with me.

21. Around 1989 or 1990, one of my doctors in New Zealand raised the subject of a potential hepatitis infection, and they carried out blood tests in relation to this. However, the test technology was not yet advanced enough in New Zealand, and I believe the bloods had to be sent to the UK for analysis. When the results came back, the doctors advised me it was negative, but this turned out to be incorrect.

22. I returned to the UK in 1997 and immediately went to see my local GP, Dr GRO-B in GRO-B in GRO-B He had been my GP prior to leaving the UK, and was also a friend. After explaining my symptoms to him, he performed blood tests which showed abnormality of the liver. He then referred me to the GRO-B GRO-B for a liver biopsy, which confirmed that I had fibrosis at that time. However, no treatment was given as HCV was not tested for. I still felt very unwell and following a number of further blood tests showing that my liver was abnormal I went back to see Dr GRO-B and had yet another blood test, this time for HCV.

23. The results of these tests confirmed that I was HCV positive. The news came as a shock to me, particularly in light of the earlier negative test in New Zealand which were incorrect as in those days, there was still minimal knowledge available in regard to HCV.

24. Dr GRO-B was very concerned about this blood test and sent me to Professor GRO-B an expert in this field, who after another liver biopsy advised me to take the Interferon and Ribavirin tablets urgently, otherwise I could be dead within three months as my liver biopsy showed Stage 5 fibrosis at that time. My HCV genotype was said to be on the lower end, so it was more likely to be treatable. I began a six month course of the treatment, and I was warned about the potential side effects beforehand.

25. I had to pay privately for the treatment and was under the care of Professor GRO-B at GRO-B a private hospital in London.

26. I was lucky to have had PPP healthcare and insurance from AXA. Otherwise, it would not have been possible for me to access the treatment.

27. I have never sought my medical records, and I never had any other medical procedure between the birth of my second daughter and when I was informed that I had contracted HCV.

28. I have always been a fit and active person and have never been an intravenous drug user. I have not received any medical treatment abroad that required a blood transfusion, and I do not have any tattoos or piercings. As far as I am aware, the only way I could have contracted HCV was through the blood transfusion I received in 1978.

Section 3. Other Infections

29. I do not believe I have received any infection other than HCV due to being given infected blood.

Section 4. Consent

30. There was no discussion in regard to the issue of consent to the blood transfusion at the time of my delivery in 197~~8~~ GRO-B because it was an emergency, and I needed the blood urgently.

31. I do not believe I have ever been treated like a guinea pig. However, when I received the interferon treatment, it had still not been approved by NICE.

Section 5. Impact

32. In the early days, before I was diagnosed with HCV, I found life difficult. My mother would tell me to carry on and not complain, and others would call me a hypochondriac. I have blanked out most of my memories of those early days, but it is ironic to think about it now. It was extremely unfair for people to think I was being precious as I could not eat certain things.

33. I studied acting in Los Angeles, and in the early days of our marriage, my first husband and I were both actors and were part of the GRO-B GRO-B

34. The lack of energy and fatigue affected my ability to work, especially because acting required getting up as early as 6 am in the morning for rehearsals, and then there were the midweek matinees. You need to have plenty of energy for that, and I did not have that. As a result, I got less and less work. I also had to raise two children.

35. The side effects of the Interferon treatment were awful. Even though it had explained that it was like chemotherapy, I was hopeful that I would be able to maintain a level of health and fitness through it. For the first few months while on the treatment, I used to take a walk around Battersea Park every day. However, gradually, it was no longer possible to do so because I was physically exhausted.

36. Some of the symptoms included fatigue, extreme headaches, sweating, feeling hot and cold and wobbly legs. I would take the injection and then feel completely wiped out for the next two days. In the immediate aftermath of taking the injection, I did not feel well, but within two days the effects were debilitating. Even when I went to church, someone had to throw a blanket on me because I was feeling both hot and cold.

37. It was a relief when the treatment ended, and indeed some of my symptoms were alleviated, which further confirmed that much of what I had been experiencing was attributable to the HCV. However, the treatment itself has had long lasting effects.

38. I suffer from wet macular degeneration of my eyes, although I don't know if this could be genetic. When I was first diagnosed with this illness, I was informed that degeneration would stop after three or four years, but it has continued to persist. I now have to receive injections in my eyes every two months. It is extremely painful afterwards, my eyes are sore all night, and I am forced to use eye drops regularly.

39. Six months after I finished the treatment, I was diagnosed with coeliac disease, and one of the liver doctors said it was due to the interferon. I had to have an endoscopy to confirm this, and it was even mentioned in a letter to me.

40. My white cell count was low after the treatment, and for most people, it bounces back. However, for me, my white cell count has never recovered. Whenever I go for a test, medical professionals are alarmed and concerned about whether I may have leukaemia or some type of blood cancer, but it has been like that for years now.

41. At some point, after I had completed the treatment, Dr GRO-B at GRO-B in GRO-B who was my new GP, contacted me in the middle of the night. He said, "I have something terrible to tell you; your HCV is back". I was terrified and immediately contacted my doctors at the GRO-B but they confirmed that my GP was wrong and I had really cleared the HCV. It appeared my GP had thought the HCV antibodies, which would show up on any blood tests, meant that the HCV was back.

42. I now have to have a fibroscan annually at King's College Hospital because it measures the amount of fibrosity in the liver. About a month ago, I went for a test, and they carried out an ultrasound instead of a fibroscan, so I will have to go back again. However, I recently received a letter inviting me for a new test, but in this letter, it again says ultrasound, so they have got it wrong a second time.

43. I have to take a strong injection for my osteoporosis now, but I have an appointment with the dentist to see if that will be alright because I am told the injection can affect the jaw.

44. I also continue to suffer from itchiness and have recently been to my GP on three occasions regarding this. They suspect it might be a blood disorder, but further tests are required to confirm the diagnosis.

45. The side effects of having HCV impeded my ability to eat certain foods and socialise, and they definitely affected my second marriage. My

husband (since deceased) would be unpleasant and intolerant about me being unable to have a drink at social functions.

46. I told my children of the HCV diagnosis, and although they were very worried about the risk of transmission, they were still supportive of me. They were older, about 20 and 21, at the time of my diagnosis, but the symptoms definitely impacted their growing up.

47. I know they are both undergoing therapy because they say they felt that my parents, rather than I, their mother, raised them for an extensive amount of time. This was due to the breakdown of my marriage and equally, I am sure, my illness was unknowingly a contributing factor.

48. I have disclosed my illness to some people, and luckily it did not have much of an impact. It has never affected me in forming future relationships because, after two husbands, a relationship was the last thing on my mind in the early days. I have had some relationships since and have disclosed the diagnosis, but no one has been too bothered about it.

49. I am quite an open person and would prefer not to keep it a secret as such. However, I try not to dwell on having had HCV, so I have not pursued things like compensation until now because I just wanted to forget it and move on.

50. I have experienced difficulty getting dentists at various points, due to my HCV diagnosis.

51. It has probably affected my life in more ways than I realise. I began travelling a lot less due to the extreme fatigue associated with travelling. I was left feeling like I had been run over by a steamroller whenever I travelled. It's no use going away if, four days after, you fee

dead, and the only thing that has changed is you have arrived somewhere new.

52. I briefly got into skincare marketing and had my own business for a while in Hong Kong. It was going quite well, and doing something I loved was rewarding. I could do it from home and still meet people, and it also had a nutritional element that made it personally beneficial for me. Nowadays, everything is online, and I don't know if it's partly because of my age, but I couldn't continue to do it.

53. The economic crash of 1987 affected my dad's businesses terribly. He was also getting old and had developed emphysema. It contributed to his poor health, and he died of a pneumonia and heart failure in New Zealand in 1996 having lost all his money.

54. When I moved back to the UK from Hong Kong in 1997 my widowed mother joined me from New Zealand and we were entirely dependent on social benefits, which was very hard. My first husband was doing quite well financially as an artist, but as we were divorced he never contributed to supporting us financially. I was already divorced from my second husband who died a year later.

55. My mum was very ill and moved in with me for about ten years until she passed away. Caring for her was very rewarding, and nowadays, I volunteer to help people who are ill by doing things like driving them to hospital appointments or just sitting and chatting to them.

56. After my father passed away, I applied for benefits and was able to secure housing benefits, and at the time, I also received carer's benefit to look after my mum.

57. I am now under the care of the NHS.

58. I sustained a fall recently on concrete while walking with friends. I had to have reconstructive surgery, and it has severely affected mobility around my hands and wrists, especially my left hand. I am currently having regular physiotherapy for this at the Chelsea and Westminster Hospital.

59. Although Dr GRO-B diagnosed me with HCV, he was also GRO-B friends with Dr GRO-B, the doctor who carried out my operation in 197~~8~~,7 so Dr GRO-B did not discuss how I came to be infected with HCV with me. I also did not pursue it because I didn't want to know. It's similar to when someone says you are going to die, you don't want to know the details of that.

Section 6. Treatment/Care/Support

60. I initially experienced some trouble accessing the Interferon treatment. I had been under the care of a private hospital at first, but they wanted me to pay and said my private health insurance did not cover this treatment as it was, at that stage considered experimental.

61. The private doctors referred me to the NHS, but the doctors under the NHS said interferon treatment had yet to receive approval for general use by NICE. In the end, I was able to have the treatment when I took AXA to the ombudsman, and whilst they said they did not want to set a precedent, I was allowed to have the treatment.

62. No one has ever offered me counselling or psychological support in relation to my HCV diagnosis.

Section 7. Financial Assistance

63. No one ever informed me about any of the Trusts or schemes that were available to people impacted by HCV. I had never heard of the Skipton

Fund or the English Infected Blood Support Scheme (EIBSS) prior to my contact with this Inquiry.

64. I have never attempted to obtain my medical records, but I plan to do so in the hope that it might be helpful when I apply to the EIBSS.

Section 8. Other Issues

65. I feel like I have been denied a successful career due to my diagnosis. It severely limited my opportunities. I also feel like I should have been advised earlier about financial assistance as it would have been really helpful when my family was struggling. I feel as though my children, and their education suffered as a result.

Statement of Truth

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

Sig GRO-B

Dated 09/02/2023