Witness Name: Sonia do Rego Barros Jordão
Statement No.: WITN7369001
Exhibits: WITN7369002-5
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SONIA DO REGO BARROS JORDAO

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 01 November 2022.

I, Sonia do Rego Barros Jordão, will say as follows: -

Section 1. Introduction

1. My name is Sonia do Rego Barros Jordão. I was born on GRO-C 1945 and my address is known to the Inquiry. I am married and I have two grown-up children. I am retired and I currently live in Manhattan, New York, with my husband.

2. I intend to discuss my infection with Hepatitis C (HCV), which I contracted from a blood transfusion following a hysterectomy operation in London.

3. This witness statement has been provided without the benefit of access to my full medical records.

4. I can confirm that I have chosen not to have legal representation and the Inquiry Investigator has explained the anonymity process to me. I do not intend to seek anonymity and I am happy for my name to appear in my statement. My family has not been involved in prior litigation.

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

6. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However I can only recall to the best of my ability, and these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Infected

7. I was born and brought up in Brazil. I met and married my husband, who worked for a large international bank, and we had two children. I worked as an office manager, but am now retired.

8. I gave birth to my second child in Brazil in 1976. I bled heavily during childbirth, and shortly after my daughter was born, it was discovered that I had a Factor 5 deficiency, or unstable Factor 5, which had caused me to bleed excessively. They were eventually able to control the bleeding and I did not require a blood transfusion on this occasion. I have a letter from my doctor that confirms the Factor 5 diagnosis. My son was born earlier, in 1972 and although I had some difficulties with the birth there was nothing to indicate any major problem then for the future.

9. Unbeknownst to me, my grandmother and father both had factor 5 deficiency so I had inherited it from them. However, I only became aware of this after I was diagnosed with the condition myself.

10. In 1979, my husband was posted to London, so we moved there as a family.

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11. In early 1986, I was told needed to have a hysterectomy. I went in for the operation on 27 March 1986. This was at the Princess Anne Hospital at BUPA Medical Centre, and I was under the care of Dr Peter Saunders.

12. This was a private hospital, which I was able to access through my husband's company insurance.

13. Before the operation, I had explained to the doctors about my factor 5 deficiency, which would increase my chance of bleeding heavily during a surgical procedure.

14. There should have been a specialist blood doctor available when I underwent my surgery, due to the added complexity of my blood disorder, however when it came to it, no such blood specialist was present.

15. I had discussed the situation at length with my doctors well in advance of my surgery, so I was very surprised that there was no blood specialist there on the day. I felt I had no choice but to go ahead without the specialist there.

16. Initially, it seemed as though the surgery had gone to plan, and that I was beginning to make a normal recovery on the ward following my operation.

17. However, I was actually bleeding heavily internally. By the evening on the day of the surgery, I was in a lot of pain and had what looked like a large football growing in my tummy. This turned out to be a massive internal haemorrhage.

18. The surgeon said I would need to be taken back down to theatre to relieve the swelling. I was taken down at around 9pm, having had the initial operation at around 8am on the same day.

19. I also required a blood transfusion to aid my recovery following this huge internal bleed. I lost 7 kilos in blood and fluids just in this one day.

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20. The haemorrhage itself was very scary. Extreme blood loss is terrifying, it feels like you are going to die.

21. The doctor told my husband that I would require a transfusion. By this time, I was drifting in and out of consciousness due to the pain and don't recall the conversation.

22. I stayed in the hospital for 2-3 weeks after surgery and transfusion. Normally with a hysterectomy it would only be a few days but I was very weak from the additional surgery and the blood loss I incurred. I had two metal clamps inserted as they battled to control the bleeding and these on occasions I can still feel internally.

23. After I came home, I remained in a weakened state. My family had to care for me as I was bedridden for 2-3 months after the surgery so I was unable look after myself. Because my recovery was slow, my mother had to come and stay with us to help look after me. It was a very complicated and difficult time.

24. I don't eat meat, so people thought my slow recovery was due to that, particularly because of the extent of my blood loss.

25. In 1987 and 1988 I had follow-up health checks with BUPA in London. I have attached a letter from May 1988 in which the doctor confirms my hysterectomy operation and the fact that I suffered the complication of internal bleeding as a result of my Factor 5 deficiency. He also mentions that there was an indication of raised liver enzyme levels in this and the previous year. **(See Exhibit WITN7369002)**

26. Eventually, I was able to get back on my feet and start living more normally, and life began to go back to how it was before.

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27. Several years later, my husband was re-posted by his bank to New York so we moved there.

28. By the early 2000s, I started experiencing several unexplained symptoms, including fatigue, weakness, body aches and loss of appetite. It was enough that I noticed it, but not enough to cause any major difficulties in my day-to-day life.

29. A friend of ours, who was also a doctor, Dr. Mario Masserano, was concerned about my symptoms and requested a specific blood test that showed I was positive for HCV.

30. I nonetheless reported these symptoms to my doctor in New York. His name was Dr Julio Messer. As a result of these symptoms, Dr Messer requested another full blood test.

31. In June 2002, the results came back showing I had again tested positive for HCV. **(See Exhibit WITN7369003)**

32. At first, although shocked by the diagnosis, I didn't realise how much of a big deal this was. It was only a lot later I understood the significance of this diagnosis and how much it would affect me. When it did sink in, I found myself worried for my future and that of my family. Was it life threatening for me?

33. My husband has worked in various countries as a bank manager, but the only place where I had a big surgery was in London. Furthermore, the only blood transfusion I have ever had was in London. Apart from the times aforementioned, I haven't been treated abroad.

34. I do not have any other risk factors for HCV. I have never used illicit drugs not have I any tattoos or piercings and I have been happily married for over 50 years. The blood transfusion is the only possible source of my infection.

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Section 3. Other Infections

35. I was tested for HIV at the same time as HCV. This was negative.

36. I do not believe I contracted any other infections. However the experience still haunts me now whenever I have to undergo any medical testing. I fear that I will discover I have acquired something else without my knowledge. I will speak later about a further illness that I believe was linked to the HCV in my system.

Section 4. Consent

37. I consented to the full blood test that uncovered my HCV in the US. I authorised everything albeit I was not aware that it specifically tested for HCV.

38. Generally I have a lot of trust in doctors and the medical profession, so if they said I needed something, I would go with it.

39. I was informed about the transfusion in London, which I knew I needed to save my life. However, I was not given any information in respect of the potential risk that a blood transfusion may carry.

Section 5. Impact

40. The HCV affected my quality of life, causing me to experience some significant symptoms, which worsened over time. They included severe weakness, debilitating body aches, nausea, and loss of appetite and some joint pain. I would often be exhausted when waking up in the morning.

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41. When I was able to eat without feeling nauseous, my palette was very limited and I could no longer eat a lot of the foods I previously enjoyed.

42. It impacted my daily living as I constantly felt weak and tired when managing my children, my husband, and the household.

43. Commitments and chores felt unbearable much of the time because I was utterly exhausted. The tiredness breeds lethargy and it becomes hard to face even ordinary tasks.

44. I was fortunate in that the HCV did not cause any issues with my relationships. Brazilians tend to have very supportive families, and this is something I have benefitted from.

45. The main thing that really concerned me and my husband was the risk of me passing the virus to our children or other relatives. This was constantly on my mind and is a difficult dilemma when it comes to showing affection through hugging and kissing.

46. My children did not experience any issues either educationally or character wise. They were already grown up when I was diagnosed. They are aware, and although they were quick to accept the situation, it remained a significant concern to both my husband and I that I could potentially be a risk to them.

47. When I received the diagnosis, we were given advice by my doctors in New York regarding precautions to take. I was told that the virus was not air borne, and was mostly transferred by blood so to be careful in that regard.

48. The doctor said it was low risk in terms of transmission to family, however I was always very careful nonetheless. I always took extra care with hygiene and cleanliness to avoid passing it on to anybody else. Despite the reassurance there is always a nagging doubt about the level of risk.

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49. My husband's employer was always very concerned with the health of their managers and their families. For example, my husband had to do a health test every year. A full blood test is part of this. He has never tested positive for HCV.

50. The HCV did not have an impact on my employment. I was an office manager in a small boutique bank, and my work was very near my house, so I was able to continue working.

51. I wasn't as bad as others symptoms-wise, I was mostly quite comfortable, and I was able to continue working quite normally for a while. However, there were times when the HCV and its side effects left me weak and unable to function properly.

52. I would end up staying in bed for long periods of time because of how I felt. Years later even after I retired, I would often still feel the exhaustion.

53. I don't feel I had any issues with socialising. The only thing was that I couldn't eat what I liked, such as certain cheeses, and no whiskey, which were things I previously enjoyed.

54. From a financial perspective I don't feel we experienced any loss as a family. Fortunately the cost of my treatment was covered by a combination of insurance and Medicare, otherwise we would have encountered a significant loss.

55. It took a long time for me to access treatment, firstly because there was no treatment available, and then once there was, we had to get through the bureaucracy of who was going to fund it.

56. I feel I am in the main a strong person, and I generally feel very healthy, all the more so since my treatment.

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57. There are still some times when I am tired and achy, and I take vitamin B which helps me with these symptoms. For example, my doctor recently gave me a vitamin B12 injection because I reported I was still feeling fatigue and some other mild symptoms associated with the condition.

58. I obviously do not know what the lasting effects of having HCV in my body for such a long time will be.

59. I am aware I have very mild cirrhosis due to long term exposure to HCV. This obviously remains a concern to both my husband and I.

60. I have never been a drinker. I love water, and tea after living in London. I haven't drunk alcohol in many years.

61. My diet is still very good. I live on vegetables and lentils mainly. Eating healthily is something that I have done for many years.

62. I have never experienced mental health issues or depression. although my mood could be low at times when infected, particularly when suffering from extreme fatigue, I never required any medical assistance. I am very religious, so when I am depressed, I turn to religion for support and guidance.

Section 6. Treatment/Care/Support

63. After I was diagnosed with HCV in 2002, my doctor in New York tried to find a way to treat the virus. It was discovered I had type 1B, and unfortunately, there was not a specific treatment for that genotype at that time. **(See Exhibit WITN7369004).**

64. I was told there was treatment for type 1A, which was not particularly effective, but nothing at all for type 1B.

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65. My doctor told me they were developing a new treatment, so I was hopeful. We just had to wait.

66. Initially, the only possible treatment was to follow a strict dietary regime. I was already a vegetarian, and I only eat healthy food. I continued this as I felt it would help me.

67. I was put under strict monitoring regarding my liver by Dr Messer. Every 3 months I would have a full blood test where the levels of the virus were checked.

68. My viral load was high but the infection wasn't affecting my general condition significantly, so fortunately they didn't need to take any more drastic measures.

69. I did not have a biopsy or scan. At the time, my doctor did not want to put me through this when he knew it something he could not cure. I think my doctor was scared to cause me to deteriorate or make things worse when he had limited options to help me.

70. We felt it was better to leave things as they were until the new treatment was developed for the particular genotype I had.

71. As mentioned, I was made aware that I do have mild cirrhosis, though my liver was not totally affected by the virus. By abstaining from alcohol and maintaining a healthy lifestyle I could help ensure that remained the case.

72. In 2011 I was diagnosed with Non-Hodgkin Lymphoma. Fortunately within 2-3 months, I was cured from that following successful treatment.

73. My oncologist did not mention any connection between cancer and HCV. However, I am aware that my doctors had to be careful regarding my later treatment for HCV as a result of the treatment I received for the lymphoma.

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So, the two conditions complicated each other somewhat. It is my belief that the cancer may have had its roots in my Hepatitis C infection.

74. It was actually my oncologist who said I needed to treat the HCV. This made me feel afraid, partly because I knew I didn't have enough money at my disposal, so it was It was a big concern that I wouldn't be able to raise the funds for treatment. Grants and funding aren't given out very easily. This made me concerned that my cancer may come back

75. I was told by my doctor that HCV can change very quickly, so she was recommended I go to a hepatologist, who would be a specialist in HCV treatment. Time was passing by now and it was several years since my successful cancer treatment, yet there had been no progress in treating my HCV.

76. I saw a hepatologist at the New York Langone Hospital. At my initial assessment, I was told there were treatments now available, which was very encouraging.

77. In 2018, a new drug suitable for type 1B was approved by the FDA. This was called Epclusa (a combination of sofosbuvir/velpatasvir). **(See Exhibit WITN7369005)**

78. In the USA, there is no equivalent of the NHS, which means most treatment has to be self-funded, or paid for by insurance schemes, or occasionally, by Medicare.

79. I was eligible for some funding from Medicare, which I was able to top up with my primary and secondary medical insurance, as well as a grant from the PAN Foundation. Fortunately this combination covered the cost of the treatment.

80. I was very lucky that we were able to get it covered without having to fund it myself, as the treatment was very expensive. My husband and I are both

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retired, so therefore have reduced income. Without the various insurances, the cost would have been prohibitive.

81. The treatment was in tablet form and the course lasted 12 weeks. I began in November 2021 and I had my last dose in March 2022.

82. Fortunately, I didn't experience any side effects from the drug. I would call it a 'dream pill'. Almost as soon as I started taking it, I felt stronger. For example, I was suddenly able to eat eggs again, having not been able to eat them for many years.

83. The first blood test after my treatment showed I was free from the virus, however they couldn't give me a clean bill of health for another 6 months.

84. Subsequent blood tests have seemed to confirm I am now free of the virus but I am currently waiting for the results of the most recent tests and I have an appointment soon about this. I am elated to be clear of this infection and although I have not suffered as badly as many others have, it has still brought a degree of misery and uncertainty to my – no, our lives.

85. I have had some dental issues recently. I have lost some teeth, which has been very painful. I think my dental issues may have been due to the HCV infection. I can't recall any issues whereby my dental treatment has been compromised as a result of the HCV.

86. In fact, I do not feel I have experienced stigma from any medical professionals.

87. I have never been offered counselling or psychological support either when diagnosed or during treatment. It would be expensive to undergo.

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Section 7. Financial Assistance

88. I have never made an application for financial support to any of the schemes. I was actually not even aware of them.

89. My husband and I don't look to see who we can get money from, this is how life is. We are very pragmatic people.

90. Recently, a relative in England sent us details of the Government backed scheme having seen it on the news and in the media. As a result, I will present a claim to the English Infected Blood Support Scheme as I believe that I qualify and any funds may provide us with a more comfortable old age.

Section 8. Other Issues

91. We don't blame anyone for what happened. We don't believe anyone did it purposely. I needed the blood transfusion to keep me alive.

92. It happened, and what's done is done. I feel we should try to correct it and prevent it from happening again, but that's it.

93. I am very grateful for the treatment to cure me. My final result following my treatment came in October this year. It came back clear, and I see this as a big victory for me.

94. My son collects whiskey. He goes to Scotland at least once a year to buy some. I am looking forward to finally being able to sample some of it with him. It will be my first drink in 40 years.

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Statement of Truth

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

Signed GRO-C

Dated 14 December 2022