Witness Name: Alan Joseph Baldwin
Statement No.: WITN4305001
Exhibits: **WITN4305002 - 003**
Dated: 14 October 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ALAN JOSEPH BALDWIN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 September 2020.

I, Alan Joseph Baldwin, will say as follows: -

Section 1. Introduction

1. My name is Alan Joseph Baldwin. My date of birth is GRO-C 1945 and my address is known to the Inquiry. I live with my wife, Pam, who has assisted me in providing this statement.

2. I am a furniture restorer and have run my own business for 30 years. I intend to speak about my infection with hepatitis C ('HCV'). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my wife and our lives together.

Section 2. How Infected

3. In 1974, I was living in Brixton, London. I was being treated at St George's Hospital, during which I was told that I was Australia Antigen, or hepatitis B ('HBV'), positive. I contracted this from sharing a water bottle on a journey back from Afghanistan. This was not a result of receiving infected blood.

4. In August 1980, my wife and I went on a camping holiday in Devon. We were in a tent in the middle of nowhere when suddenly I felt an excruciating pain in my stomach. My face also went a nasty colour.

5. My wife called a local doctor, who managed to find us in a tent in the middle of an isolated field. He rushed me straight to the Royal Devon and Exeter Hospital where I was found to have a ruptured duodenal ulcer. I was then taken straight down for an operation.

6. I woke up half way through the operation as the anaesthetic had worn off. I remember seeing all the surgeons surrounding me covered in blood, and I then said that I had previously had hepatitis B. They were shocked and went to scrub off as soon as I told them. I recall this event vividly, in particular the amount of blood I had lost. This was clearly visible on all the surgeons' white coats. As a result, I believe that I must have had a blood transfusion during this operation.

7. After the operation I felt alright, and I continued life as normal. Then, in 1984, I was diagnosed with throat cancer. I was soon offered radiotherapy, which was successful in clearing the cancer. The cancer was in remission for the following 17 years.

8. In 2000, I began to notice a lot of mucus and catarrh in my throat. I went to see my GP, who told me that it was highly unlikely to be a recurrence of the throat cancer. He said that there was a 95% chance of the cancer not reoccurring in the same place.

9. This continued for around 18 months without any formal diagnosis. I was reliant on herbal remedies to relieve the symptoms. Then, in 2001, I was finally diagnosed with a recurrence of the throat cancer from 17 years earlier.

10. The cancer had grown on my vocal chords. As I had previously been treated with radiotherapy, this was no longer an option for treatment. They first gave me laser treatment in an attempt to burn the cancer off, which worked for a while but ended up coming back. I was then told that the only option to completely clear the cancer was a total laryngectomy.

11. I had a laryngectomy in 2003 to remove the cancerous growth. I was fitted with an indwelling Blom-Singer voice prosthesis which allows me to talk. I am able to talk by pressing on the voice box. At first this had to be replaced at a hospital on a frequent basis, ranging from every month up to every 3 or 4 months. I was later offered lessons showing me how to remove and replace the prosthetic voice box myself.

12. Aside from this treatment, I was largely in good health for 25 years from 1980 to around 2005. In early 2005 I began to suffer from extremely itchy skin. This was driving me mad, and it became unbearable for around 4 or 5 weeks. I finally saw my GP, Dr Morgan who took blood tests from me in order to establish the cause of my itching.

13. Around 2 weeks later, I was called by Dr Morgan who told me over the phone that I had HCV and I was asked to attend an appointment at the surgery. I attended the appointment on 29th April 2005 and sat in a room with a doctor Morgan, who explained to me about infection management such as not sharing toothbrushes and razors with anyone. I was also told that I would be put on a course of interferon to treat the HCV infection.

14. When I was informed of my diagnosis, I assumed that this was related to my previous infection with hepatitis B. However, I was found to be hepatitis B negative in February 2005, which had been cleared without

any specific treatment. I was therefore confused at how I could have contracted HCV, an infection that I knew next to nothing about.

15. I was subsequently referred to Odstock Hospital, Salisbury. Julia Robathan, who I believe was the head of the hepatology department at the hospital, asked me a number of questions about my background and what I did for a living. I just told them that I lived a pretty normal life. I was not asked if I had ever had a blood transfusion. It was not explained to me that HCV could cause cirrhosis of the liver or possibly liver cancer. Rather, it was made to seem like a relatively inconsequential infection.

16. My wife Pam was not at all worried about the infection, and we were not told that I could potentially transmit the virus to Pam through blood to blood contact. I was only told that I could never donate blood again.

17. I was offered treatment for the HCV by Julia Robathan at the Odstock Hospital almost straight after being informed of my diagnosis. I was offered an interferon-based treatment, which included a pink medicine in a bottle that was part of the treatment. The course of interferon treatment was due to last for 9 months. I found a diary entry of that time that suggests that my treatment started 6 June 2005 and ended 13 March 2006. My last injection of interferon was 7 March 2006. I am unable to recall the exact dosages of interferon.

18. The hepatology department at Odstock Hospital showed me how to self-inject the interferon. I believe that I self-injected the interferon into my stomach around once a week. This was not a nice experience, but I was determined to get it done and clear the HCV infection.

19. I had a liver function test prior to starting the treatment, though I do not recall if I had a liver biopsy before commencing treatment. I attended a check-up at the hospital once a month for my viral load to be monitored. At each monthly check-up, the tests showed a reduction in my viral load. By the end of the 9 month course of treatment, the HCV was undetectable. My diary shows that I had 2 blood tests on March 20 2006

and that I would receive no more drugs. I was relieved that the treatment had ended.

20. I had a further check-up 3 months later that again showed the HCV was undetectable. The HCV was undetectable at a further check-up 6 months later, and then an additional 12 months later. My liver was checked a year ago, which showed no abnormalities or problems. I still feel some itching occasionally today, but this is minimal in comparison to before my HCV treatment.

Section 3. Other Infections

21. I do not believe that I had any infections other than HCV as a result of receiving an infected blood transfusion.

22. I tested positive for HBV in 1974, but this was not caused by infected blood. I tested negative for HBV in 2005.

Section 4. Consent

23. I do not believe that I was treated or tested without my knowledge or consent.

Section 5. Impact

24. I did not experience any noticeable mental or physical effects as a direct result of my infection with HCV. I only suffered from unbearably itchy skin that had begun to affect my sleep. If I had not gone to my GP with this, and subsequently been tested for HCV, I would never have suspected that I was HCV positive.

25. The side-effects of the interferon treatment were completely debilitating. I was totally wiped out as soon as I self-injected the interferon. This

lethargy would stop me from functioning and performing even the most basic day to day tasks.

26. I also continued to suffer from painful itching of the skin. I took painkillers to relieve this and to help me sleep, but this proved to be fruitless. The itching continued throughout the entire 9 month course of treatment and for some time after completing the treatment.

27. The extreme fatigue meant I was barely able to work. Thankfully, my wife Pam was working during my treatment and able to provide for us at the time. This was a help, as having reviewed my company accounts I earned next to no money over this 18 month period. I had worked hard to establish my furniture restoration business in the area since 1990, and it was proving to be fairly successful. Then the treatment began, and this all but stopped, at best work was spasmodic. I was unable to work for 18 months, up until the end of 2006, which was devastating for the business. I have worked hard since to re-establish my business, and I am still working today.

28. Being out of action for 18 months certainly affected my social life. I was too fatigued to see anyone or to do much at all. This all happened whilst I was learning to adapt to having a prosthetic voice box. I initially had to travel to Southampton whenever it required changing. This became a physically-draining task during and after the interferon treatment, as well as hindering my independence enormously. I also had to attend Odstock Hospital for check ups relating to my prosthetic device.

29. Though very fatigued, I managed to get to University College Hospital, London, where I was offered lessons showing me how to remove and change the voice box myself. Though this was difficult and extremely tiring, it was a vast improvement that allowed me to regain some independence. I was thereafter able to travel without worrying about being near to a hospital in case the voice box needed urgently replacing.

Section 6. Treatment/Care/Support

30. I was offered interferon treatment almost straight after being diagnosed with HCV.

31. I was not offered any form of counselling or psychological support in consequence of my infection with, and treatment for, HCV. I do not believe that I needed it.

Section 7. Financial Assistance

32. Although I cannot recall exactly, I believe that I heard about the Skipton Fund through the hepatology department at Odstock Hospital in Salisbury. Prior to applying to the Skipton Fund, I applied to the Royal Devon and Exeter Hospital for my medical records pertaining to my operation there in 1980.

33. I received a letter in response from Sharon Rowland (Deputy Data Protection Officer, Royal Devon and Exeter NHS Foundation Trust) dated 21 February 2006 and enclosed as exhibit **WITN4305002**. This letter reads: 'I have searched our Patient Administration System for information, but unfortunately due to the Health Record Retention and Destruction Policy of this Trust, our records are only kept for a period of 8 years without any further attendances. Therefore, I can confirm that any records that were held on your behalf were unfortunately destroyed on the 11 May 2005.'

34. Despite the destruction of my medical records, I applied to the Skipton Fund on 11 October 2006. I enclose a scan of my application form as exhibit **WITN4305003**. My GP, Dr Mark Morgan of The Surgery, Sixpenny Handley, Salisbury completed section 4A that includes reference to a discharge letter from Devon Area Health Authority after my operation in August 1980. In section 4A(ii), Dr Morgan answered 'No'

to the question 'Do any records exist of this possible occasion of infection?'

35. I received a letter in response from the Skipton Fund soon after my application in which they said they were unable to progress with the application because my doctor was unable to complete the evidence proving that I had a blood transfusion. Although I had a letter proving that my medical records relating to my operation in 1980 were destroyed, I was unable to continue with the application. I felt that I had reached a dead end and I decided to discontinue with the process of applying to the Skipton Fund.

Section 8. Other Issues

36. As my medical records have been destroyed, I am unable to prove that I received a blood transfusion during my operation in August 1980. This is through no fault of my own.

37. I have no other way of proving that I had a blood transfusion. I could not have been infected with HCV in any other way. I have never been an intravenous drug user, I have never been promiscuous and I have never received medical treatment abroad. I therefore believe that the only explanation for my infection with HCV is that I received an infected blood transfusion during my operation in 1980.

Statement of Truth

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

Signed GRO-C

Dated 14/10/2020.