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Witness Name: Wayne John Taylor
Statement No.: WITN5136001
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Dated: 21 October 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF WAYNE JOHN TAYLOR

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 September 2021.

I, Wayne John Taylor, will say as follows: -

Section 1. Introduction

1. My name is Wayne John Taylor. My date of birth is GRO-C 1953 and my address is GRO-C GRO-C.

2. I retired in 2003 through ill health as a result of having hepatitis C ("HCV"). I have previously worked in the merchant navy as a cook, a labourer for the local council, in the coal industry for the National Coal Board and as a self-employed heavy goods driver up until my early retirement.

3. I was married for 16 years before divorcing in 1992, which I put down to my HCV. We had two children, a daughter now aged 41 and a son now aged 34. I have seven grandchildren. I live alone in a council house.

4. I intend to speak about my infection with HCV. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.

Section 2. How Infected

5. I left school aged 15 and worked as an apprentice machinist for 6 months. I soon realised that it wasn't for me and I joined the merchant navy aged 16. I was in the merchant navy from 1970 to 1974, working primarily as a cook on cargo ships.

6. GRO-B

7. In 1991 I decided that I would get a vasectomy. GRO-C GRO-C and we did not want any more children so I decided to take the initiative and have the procedure.

8. I had my vasectomy at South Tyneside Hospital one Tuesday in 1991. I was in a room with two other men at the same time who were both having the same procedure, by different medics. During the operation, there was a problem with one of the other men. All the doctors stopped and rushed over to him to help out. Once they had resolved whatever the issue was, they returned to me and the other male and finished the job off.

9. The following Saturday I was playing cricket for my local team. I was the opening batsman and, when facing the first ball, I became inexplicably frightened. This was completely out of character and I had never felt fear like this before. I was trembling and had no confidence whatsoever in facing the opening bowler.

10. Over the following weeks, this feeling increased and during the next 5 to 6 years my personality changed enormously. I used to be a healthy, happy-go-lucky type of man, with a good nature and a kind personality. This began to change and I soon realised I was becoming aggressive, argumentative, angry and intolerant.

11. Over this period, I also began to suffer from regular illnesses such as colds and flu. I felt constantly fatigued and I lost all enthusiasm for life. I had left my job in the coal industry and, from 1993 onwards, was working as an HGV driver. My tiredness became so debilitating that I was starting to fall asleep at the wheel during long journeys.

12. On one occasion in 1997 I was listening to Radio 4 in my wagon and there was a story on HCV. I remember I was in Wakefield at the time. The programme shone a light on hepatitis B and C and there were a number of people who were discussing all their symptoms. I recognised and related to all these symptoms and instantly I was convinced that I had HCV.

13. I visited my doctor after listening to this programme. My GP was Dr GRO-D at GRO-D in South Shields, who was later struck off for failing to check whether a patient was allergic to penicillin. The patient had a serious reaction but I am not aware of the outcome.

14. I previously thought that it was only intravenous drug users who contracted HCV but it was clear from the radio programme that the contributors did not fit into that category. I phoned Dr Naroz and said that I had heard that an ex-girlfriend of mine had recently been diagnosed

with HCV and had died. I did this solely to ensure I got an appointment and a blood test. It was a complete lie.

15. When I explained my symptoms to Dr GRO-D and told him what I had heard on Radio 4, he was not convinced. He seemed to know very little about HCV and was reluctant to do a blood test. I eventually persuaded him to do a blood test for HCV, which one week later came back positive.

16. Upon hearing my HCV diagnosis, I asked Dr GRO-D what I should do now and he said he did not know anything about HCV as he had never diagnosed someone with HCV before. I had basically diagnosed myself and just needed the test to confirm what I had thought. I eventually managed to get a referral to the hepatology department at Freeman's Hospital, Newcastle, which is run by Dr Maggie Bassendine.

17. Dr Bassendine took liver tests and tested my HCV type. I was found to have genotype 1A, which I was told meant that I contracted HCV in the UK. Dr Bassendine also informed me that I had had HCV for approximately 20 years, which would equate to being infected around the late 1970s.

18. After my diagnosis with HCV I had to tell my ex-wife and my children. They were all tested and thankfully returned negative results.

19. I was offered treatment for the first time in 1999. This treatment consisted of interferon and ribavirin and was meant to last for 48 weeks. I believe it was a trial treatment.

20. I injected interferon every second day and took a ribavirin tablet every other day. Within 8 hours of the first interferon injection I was in bed. It was like the worst case of flu imaginable. I couldn't get out of bed and, needless to say, I couldn't work as an HGV driver, which meant I was earning nothing.

21. Within a month of starting this course of treatment I had lost 2 stone. My body was aching from head to foot and even my gums were hurting.

After 5 to 6 weeks of barely coping with the treatment, I phoned the hepatitis nurse and told her that I couldn't tolerate it anymore. She told me not to worry and said that no one else could deal with the side-effects either. I came off this treatment.

22. I began a second course of interferon and ribavirin treatment in 2002. This time I injected interferon once a week and managed to complete the 48 week course. Despite this, the virus was still detectable and my viral load showed no signs of improvement. The side-effects were again severe but not quite as intolerable as the first treatment. I believe this was because the injections were less frequent.

23. I was incapacitated and unable to work during this treatment. I experienced the same side-effects, namely tiredness, a lack of motivation and I lost all interest in life. I strived to complete the treatment but it didn't work in clearing the virus.

24. After this second course of treatment, I decided to retire due to illness associated with HCV and the side-effects of the treatments. I was offered a third course of interferon and ribavirin two to three years later, which I believe was also a trial. This involved injected interferon once weekly and taking ribavirin tablets daily.

25. It was not explained to me how this course of treatment was, if at all, different to the last treatments. All they said was that it had improved since the last treatment. I completed a 48 week course. The side-effects were the same but not as severe.

26. I suffered from more mental, as opposed to physical, side-effects during this course of treatment. My brain was constantly looking for this invisible thing in my body. During my waking hours, I couldn't switch my mind off as I knew it was in me but it was if I couldn't find it.

27. Mentally and physically I was tired all of the time. I could sleep for 16 hours a day. I began to sleep as a way of avoiding the mental side-effects when I was awake. I lost all enthusiasm for life and it was like I had a

mental crisis. I was unable to stop or control worrying and the treatment was again unsuccessful in clearing the virus.

28. I realised that I was suffering from depression during this course of treatment. As a result, I spoke to Dr Bassendine who said that I could take antidepressants. She referred me to a psychiatrist, called Dr Sanjay Rao, at the Royal Victoria Infirmary, Newcastle.

29. Dr Rao prescribed me with 10mg of citalopram, which was later changed to sertraline. After taking this my brain went 'electric' and I began to feel a lot better. It made me feel more able to tolerate the treatment. I remain on antidepressants to this day as a result of the trauma I experienced when undergoing these treatments.

30. After completing this third course of treatment it took me the best part of a year to fully recover. It was explained to me that there were remnants of the medication still in my body and it would take up to 9 months for this to fully clear. By this time my viral load had continued to rise.

31. I was offered a fourth course of treatment in 2012. This treatment consisted of interferon, ribavirin and telaprevir, which was a new drug. It was initially meant to be a 3 month course. I wasn't sure if I could face another course of treatment as every time I started it took me up to 2 years to fully recover.

32. I was monitored for the first 3 months and after completing the 3 month course I was told that my viral load count was 269, down from the hundreds of thousands. For the sake of a viral load of just 269, I had to continue with interferon and ribavirin for a further 9 months.

33. The telaprevir medication was like liquid dynamite. I heard of lots of people who were forced to stop it as it was causing agonising burns to their anuses. It was toxic and every time I went to the toilet my stools would burn my anus. It also burned my face. I managed to deal with this but it was horrendous. After the 3 months, when I returned to just interferon and ribavirin, these side-effects stopped.

34. At the end of the 12 months I was clear of HCV. I was tested 6 months after the end of the course and the HCV was undetectable. I was then discharged from the care of the hepatology department at Freeman's Hospital.

35. After clearing the HCV my health began to improve noticeably. I remember on one occasion I was sitting in a chair in my bedroom and black spots began to appear in my eyes. I could hear and feel the rays of sunlight hitting my face. I now believe this was the effect of the virus finally having left my body. It was like the character in the film 'The Green Mile' when all his anxieties and pain was leaving him.

36. A few months after finishing the treatment I felt like a new man. I was invigorated and renewed. I felt brand new and like I had come back to life.

Section 3. Other Infections

37. I do not believe I received any other infections, when I contracted HCV.

Section 4. Consent

38. I believe that I consented to all testing and treatment I received for my HCV.

39. I felt like a human guinea pig throughout all courses of my treatment, but I consented to all of this. I was willing to try anything and I complied with all the testing throughout my treatment.

Section 5. Impact

40. I attribute the breakdown of my marriage to my HCV infection. My personality completed changed after I contracted HCV. I became aggressive and moody, which took a toll on our relationship. When we separated I lost my house and my children.

41. I was working as an HGV driver for 6 days a week and had no home to return to for the 7th day. The council initially refused to re-house me and I was forced to sleep on my sister's sofa when I wasn't on the road.

42. When I was eventually rehoused I felt isolated and lonely. I did not seek any form of sexual relationships because of my HCV infection. I also lost a lot of friendships as they felt uncomfortable about my HCV status. I have never tried to hide my HCV, though I noticed that friends were awkward and uncomfortable around me. There were certainly negative connotations. I remember one friend used to give me an old cup whenever I visited.

43. My children were the reason why I fought through all the horrible treatments. They were what made me want to stay alive. I used to be very emotional around them and I would cry a lot, which was out of character. I was an emotional wreck and they could see the effects the treatment was having on me. They wanted me to stop the treatment having witnessed my weight loss and the pain it was causing me. I looked like an old man sat in a chair at home, only going out for hospital appointments.

44. I was unable to work due to the severity of the side-effects that the treatments inflicted upon me. As I was self-employed as an HGV driver I received no income whatsoever. I was forced to apply for sickness benefits which were initially refused. The job centre told me that HCV was not a recognised illness with regard to sickness benefits.

45. I fought hard to get HCV recognised and I was eventually awarded benefits with the support of Dr Bassendine. I had a lot of problems with the job centre over the years. I used to miss appointments because of

the treatments I was on, which led them to stop my payments. I am now on a state pension and I receive a private pension from the coal board.

46. The HCV treatments had a detrimental effect on my mental health which persists to this day. During the third course of treatment I began to hear demons in my head telling me that I should infect people. I wanted to kill myself or kill other people. It was like the virus was trying to get out of my body and get into somebody else's.

47. I lost the ability to concentrate, which was another factor in forcing my early retirement. I suffer with brain fog; my brain freezes from time to time and I regularly lose my chain of thought.

48. I represented the Liver North Charity, who were connected to Freeman's Hospital, as a liaison. I was approached by the chairman as they didn't have a spokesman for HCV at the time. I was the face of the 'Look at your past' campaign, which encouraged people to get tested for HCV. My story appeared in a number of publications in 2005-2007 and I have exhibited these articles at the end of this statement.

49. After the campaign we were inundated with phone calls from people all over the country who had received blood transfusions and were later found to be HCV positive. It became clear to me that there were lots of people who had been infected as a result of contaminated blood, and hardly anyone was an intravenous drug user. I realised something bigger was afoot.

50. After my diagnosis with HCV I informed my dentist. The receptionist told me that I had to come back at the end of the day for my treatment. I asked why and she said that it was a highly contagious condition. The dentist and nurses wore a lot of protective equipment and masks, and it was obvious that more precautions were being taken. I felt like I was a pariah; they clearly didn't want to risk cross-contamination.

51. On one occasion I had to suggest to the dentist that he should wear gloves, to which he replied that there was no need because he is

vaccinated. I said that he couldn't be vaccinated for HCV as there is no vaccine. They clearly weren't aware of this and had confused HCV with hepatitis A & B. I believe this was sometime in the late 1990s at Scrafton and Bond dentists in Flagg Court Health Centre, South Shields.

52. In the run up to the Inquiry interview for my statement, it has caused me to think harder about my years with HCV. Reliving all these events has caused me to feel like I have post-traumatic stress disorder. Bringing it all up again has made me anxious and caused my arms and hands to tremble uncontrollably. I feel like an innocent victim who is unable to prove the cause of my HCV infection.

Section 6. Treatment/Care/Support

53. I did not experience any difficulties in obtaining treatment in consequence of my HCV infection.

54. I was not offered counselling or psychological support in respect of my HCV infection. I had to push Dr Bassendine to refer me for psychiatric support during my third course of treatment.

Section 7. Financial Assistance

55. I learnt about the Skipton Fund through the Hepatitis C Trust. I applied to the Skipton Fund in the mid 2000s. In my application I still maintained that my HCV had come from a sexual relationship with a previous girlfriend in the early 1990s. This was never true and I used this simply to get a test for HCV. The truth, as I see it, is my HCV stemmed from my vasectomy in 1991 when my whole personality changed. This, having reviewed my whole life in my head on countless occasions, is the only thing I can see that has caused my HCV infection. I believe this is backed up by the fact my genotype 1A suggesting that my HCV was derived from the UK and not from sex workers abroad.

56. My application to the Skipton Fund was rejected on the basis that there was no proof that I had got HCV as a result of infected blood from the NHS, whether directly or indirectly through a sexual partner. I just accepted this decision and moved on.

Section 8. Other Issues

57. I feel a great sense of injustice. I am an innocent victim who doesn't know how I was infected. I had no knowledge of blood-borne viruses before my infection with HCV and I didn't know what to do. This went on for a long time and has made me physically and mentally sick. It has ruined my life, without a doubt. I thought I had my life plotted out but this all changed after my HCV infection.

58. I now regret that I was disingenuous when I first approached my GP to get an HCV test. I didn't know anything about HCV, just what I had heard on the radio. I didn't believe anything else in my life could have caused this. Once I learned more about HCV, the only thing I can go back to as the cause is my vasectomy in 1991 and how it made me feel after the procedure. My health prior to this was fine but this all changed. I do not believe I got HCV from anywhere else and the reason I stuck to the story about an ex-girlfriend when I applied to the Skipton Fund was for consistency and I didn't want my story to change.

59. I have tried to get my medical records from hospitals but they have been destroyed after so many years.

60. Money is of no interest to me. I am telling this story because of the injustice I feel about what has happened to me. I want my story to be heard.

61. I would like to offer some documents to accompany my statement, in the form of published articles that refer to me. They are not proof of anything

though I do believe that they support my 'story' in that the articles in question were written some years ago.

62. WITN5136002 is from TV Choice magazine dated 14-20 April 2007. I produced a scan of the cover and page with the article/NHS promotional feature.

63. WITN5136003 is from What's on TV magazine dated 4-10 February 2006. I produced a scan of the cover and page with the article/NHS promotional feature.

64. WITN5136004 is the 'Health' page of The Evening Chronicle, a local paper, dated October 3 2005, in which it refers to me taking part in a NHS campaign to raise awareness of HCV, along with my 'story'.

Statement of Truth

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

Signed GRO-C

Dated 21·10·2021