Witness Name: Ronald Edge
Statement No.: WITN0257001
Exhibits: WITN0257002
Dated: 2 April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF RONALD CHARLES JOHN MICHAEL EDGE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 December 2018.

I, Ronald Charles John Michael Edge, will say as follows: -

Section 1. Introduction

1. My name is Ronald Charles John Michael Edge. My date of birth is GRO-C 1948 and my address is known to the Inquiry. I am a retired taxi driver and I live with my wife whom I have been married to for 39 years. We do not have any children together.

2. I was diagnosed with mild Haemophilia A when I was approximately 9 – 11 years old. In this statement I intend to speak about my infection with the Hepatitis C Virus (HCV), which I believe I contracted through treatment I received for Haemophilia. I intend to speak about how the infection affected me, the treatment I received for HCV and the overall impact it has had on my life.

3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Background

4. I was born in Belfast however, in the early years of my life my family and I travelled all over the world as my father was an English soldier in the army. We spent time in Africa, Germany and Scotland.

5. I was diagnosed with Haemophilia in Scotland, either in Glasgow or at the Edinburgh Infirmary. I cannot now recall which one. When I was first diagnosed, I was told that I was not allowed to do any sports or physical education at school. I was also initially injected with snake venom as treatment. It was used to help my blood clot before Factor VIII treatment was available.

6. From Scotland my family and I relocated to Sussex. We settled in GRO-C in Kent around 1965 when I was about 16 years old. When I was in GRO-C I went to the Isle of Thanet District Hospital in Margate for treatment as a Haemophiliac. I went there for treatment whenever I suffered from a bleed.

7. At the time I had to go for treatment quite often, at least every couple of months. I worked as an apprentice mechanic from the age of 16 until I was approximately 21 years old. Certain tasks in my job were causing bleeding to my knuckles in particular. I was advised to avoid lifting anything heavy and to find an office job instead.

8. I was initially under the care of Dr Sterndale, a specialist in the Pathology Department of the Isle of Thanet District Hospital. When Dr Sterndale left the hospital, his under study, Dr Winter, took over as the person in charge. I think that occurred in the early 1980s. At the same time, Dr Winter moved from the Isle of Thanet District Hospital to the Kent and Canterbury Hospital as a proper Haemophiliac Centre was developed there.

9. I continued to see Dr Winter at the Kent and Canterbury Hospital for treatment. This continued to be quite often as in my late teens and 20's I often suffered from bleeding from alcohol related injuries. I think I drank quite heavily at the time as when I was first diagnosed with Haemophilia, I was told that I would only live until I was 20 years old. That bothered me a lot at that time.

10. I also saw Dr Winter for routine check-ups, initially every 6 months. Over time, the check-up appointments dropped down to once a year.

11. When I received treatment both at the Isle of Thanet District Hospital and then at the Kent and Canterbury Hospital, I was given Factor VIII. At the time, Factor VIII was referred to as 'sludge' or plasma.

12. As far as I am aware, I only received Factor VIII. There is a possibility that I may have received cryoprecipitate when I first started receiving treatment at the Isle of Thanet District Hospital. On some occasions, I recall having to wait a while before receiving treatment at the Isle of Thanet District Hospital. I am not sure why I had to wait. It may have been because I was given cryoprecipitate on those occasions, but I cannot be sure.

13. When I was given Factor VIII, it was sometimes given to me through a drip. Otherwise it was injected into a vein in my arm. When I was treated, I would generally spend a day or two in hospital.

14. The Haemophilia Centre in the Kent and Canterbury Hospital issued me with a card that details my blood type and Haemophilia condition **[WITN0257/002]**. I generally carry this card around with me.

15. Sometime in the early 1980s, I cannot recall when, my mother gave me a leaflet regarding AIDS. My mother used to give money to the Haemophilia Society and had obtained the leaflet from them. My mother told me to read the leaflet as it was important. I read the leaflet and remember that it mentioned an 'acquired immune system' and that you could die from AIDS.

16. While I cannot recall the exact content of the leaflet now, at the time it put me off receiving Factor VIII. I was scared to receive Factor VIII as I thought it would kill me. As a result, I declined any injections or treatment for Haemophilia for 20 years from that time onwards. I put up with the bleeds and bruises even if it lasted for a few weeks or months at a time.

17. I still continued to attend routine check-up appointments with Dr Winter throughout this time. When he asked me how I was, I would lie to him and tell him that I did not have any joint bleeds.

18. As well as Factor VIII, I have received approximately up to 10 blood transfusions. The first blood transfusion I recall receiving was when I was about 3 or 4 years old as I had fallen from a balcony and suffered injuries. I believe I received that blood transfusion in Germany.

19. I received several other blood transfusions in my late teens and 20's due to alcohol related injuries. I also recall receiving a blood transfusion when I suffered from a stomach ulcer in my 20's. I have not had any blood transfusions over the past 30 – 40 years.

Section 2. How Infected

20. I believe I was infected with HCV in November 1977 at the Isle of Thanet District Hospital, where I received Factor VIII treatment for Haemophilia.

21. I believe I was infected at that time as following my treatment on that occasion, I experienced a lot of sudden internal pain throughout my body. It was the only very bad experience I had following receiving Factor VIII treatment. I remember that I did not have any signs of bleeding such as bruising but that the pain I was experiencing was intense.

22. I was 29 years old at the time. I was taken to the closest main hospital, Willsborough Hospital. I spent a couple of days at Willsborough Hospital and

I was then transferred back to the Isle of Thanet District Hospital where I spent a further few days. From there I was sent to Taplow, the Royal Canadian Hospital. I stayed there for approximately 6 weeks.

23. At Taplow I was first told that I had a virus disease. Their diagnosis then changed and I was informed that I had developed arthritis. They initially believed I had Rheumatoid Arthritis. They then thought I had Polyarthritis before finally concluding that I had Osteoarthritis.

24. The medical staff at Taplow were aware that I was a Haemophiliac. They told me that the arthritis I had developed was as a result of age and did not say that it was attributable to anything else.

25. While I was at Taplow I was given approximately 30 tablets to consume per day. My left leg was placed in a plaster cast and my right arm was assisted with a hand/arm support in an effort to straighten them out. The arthritis however locked some of my joints and one of my fingers on my right hand remains permanently bent.

26. In the early 1990s, I then attended a routine check-up appointment with Dr Winter at the Haemophilia Centre in the Kent and Canterbury Hospital. During this appointment he told me I had contracted HCV and there was treatment available.

27. I am not sure whether Dr Winter told me how I had been infected with HCV. He may have told me that it was from the Factor VIII treatment I had received in the past but I cannot be sure. In any event, I recall at the time presuming that was how I had been infected.

28. Dr Winter was unable to point to a particular time in which I could have been infected with HCV. He did not tell me how long I would live for or provide me with any advice regarding the consumption of alcohol, risk of transmission or the impact it may have on my general health going forward. I cannot recall receiving any advice regarding the risks in having children or what

information I needed to share with other health professionals such as dentists.

29. Dr Winter did offer me treatment for HCV. I was offered Interferon and Ribavirin. He explained that the 'effectiveness' of the treatment was only at a rate of 25 – 30%. Dr Winter also explained that there were side effects associated with the treatment and that it would be difficult to take. For these reasons I declined the treatment at that time.

30. I am of the view that I should have been informed that I was infected with HCV much earlier. I do not think there was any 'cover up' on Dr Winter's part. Dr Winter and I had a good relationship. He was heavily involved with the Haemophilia Society. I believe that if Dr Winter had known that I had HCV earlier, he would have told me.

31. However, I am of the view that Dr Winter did not give me adequate information when I was told that I had HCV. After being informed, my wife and I had to ask Dr Winter about the risks of transmitting HCV to other people during our next appointment with him. He simply told my wife that she needed to see her own General Practitioner but did not warn me about the risk of transmitting HCV through blood contact. I am sure that he was aware of the risk as I recall on one occasion I had a bleeding finger around him. As blood squirted out of my finger he leaped back quite suddenly. I remember thinking that if he was that scared of my blood he must have known something about the risk of transmission through blood.

32. Following my diagnosis of HCV, I started treatment again for Haemophilia. Instead of Factor VIII, I started taking 'artificial blood' as it was referred to then.

33. In 2005, I decided to have treatment for HCV. I think I made that decision as Dr Winter had told me that the effectiveness of the treatment available

had improved. I did not think the treatment would get much better so I decided to accept the treatment at that time.

34. I started treatment for HCV in November 2005. I received the treatment from the Kent and Canterbury Hospital. The Charge Nurse at the hospital, Bryan Jones, injected Interferon into my stomach at the hospital every week. I am aware that some people injected Interferon into themselves at home but I chose to go into the hospital for the injections instead. I was also given Ribavirin tablets.

35. My treatment for HCV finished around June 2006. I was regularly checked throughout the course of my treatment. Bryan Jones would check 'my numbers' and tell me if my numbers in relation to HCV were up or down. I am not sure what the numbers actually referred to.

36. At the end of my treatment, Bryan Jones told me that I had been treated. I also saw a consultant at the hospital, Dr Eliot. I asked her if I had been cured. She did not say that I was cured but told me that the HCV had been 'eradicated' by the treatment.

Section 3. Other Infections

37. I believe that I developed arthritis from the Factor VIII treatment I received as well. After I was first diagnosed with arthritis at Taplow, I spent approximately 1 year off work. I could hardly walk and experienced a lot of pain in my hands and feet in particular.

38. I had to plead for painkillers from my General Practitioner. I was eventually prescribed Naprosyn. Unfortunately, the painkiller contained a lot of aspirin and gave me a stomach ulcer. As a result, I had to stop taking the pain killer.

Section 4. Consent

39. I do not think that I have ever been treated or tested without my consent. I consented to the treatment I received for both Haemophilia and HCV. On occasions I have even declined treatment for both Haemophilia and HCV as I have already detailed above.

40. While I consented to the various treatments I have received, I believe that I was not provided with sufficient information regarding those treatments, both for Haemophilia and HCV. Information regarding the risks associated with the respective treatments and the effects of those treatments were never provided or explained to me.

41. While I have not been given any treatment explicitly for the purposes of research, as a Haemophiliac to some extent I feel like I have been treated like a "guinea pig." I cannot explain why I feel that way. I do note that on one occasion Dr Winter refused to give me Factor VIII treatment when I asked for it. Dr Winter's excuse at the time was that the treatment was expensive and that I did not need it, or something to that effect.

Section 5. Impact

42. I was in my 40's when I was first told that I had HCV. It took some time for the news to sink in properly. Once I realised what had happened to me my wife and I were devastated. I had been given a disease through no fault of my own. I was particularly un-happy as I had stopped receiving Factor VIII treatment for approximately 20 years in an effort to avoid getting A.I.D's.

43. I was also worried that I had infected my wife with HCV. GRO-C GRO-C GRO-C. I had heard that HCV could be transmitted through sex and I was worried that I would infect her.

44. My wife and I did not tell anyone that I had HCV. I was ashamed of it. I was worried that people would think that they would catch it from me. I also knew that HCV was associated with drug users. I am not a drug user and I did not want to be associated with that.

45. I did not tell anyone at my own place of work. When I took over 6 months off work to receive treatment for HCV, I told my colleagues that it was for something to do with my Haemophilia only. I actively concealed the fact that I had HCV.

46. When I received treatment for HCV, side effects that I experienced included fatigue, sweating throughout the night and eczema all over my body. As a result of the eczema, I bled a lot as I would scratch my skin. I asked Dr Winter for treatment to help my blood clot but for some reason he declined to give me the treatment at the time. Eventually the Charge Nurse, Bryan Jones, gave me treatment for my Haemophilia.

47. As a result of the treatment I received for HCV, I lost a lot of weight. When I received the treatment I was asked whether I wanted the highest dose possible. I said yes as I wanted to get rid of the infection. I went back to my job as a taxi driver straight after my treatment for HCV concluded as my wife and I needed the income.

48. From the HCV treatment, I experienced depression. I had suicidal thoughts and told Dr Winter about the way I was feeling. He told me that I would never act upon those thoughts, as I was not in a 'manic' depressive.

49. While my wife and I initially worried about HCV a lot, in time we really viewed it as just another thing to cope with in our lives.

50. In general terms it is difficult to say how HCV specifically affected my employment and life. As a result of my Haemophilia, my employment did change a lot throughout my life. After leaving school at the age of 15 I worked in a range of roles including serving petrol by hand and working as

an apprentice mechanic, coal man and store man. As a result of the arthritis I developed, my hands and fingertips became weak and stiff. I experienced a lot of pain and my hands and feet would seize up if I did not move them for long periods of time. That is why I decided to take a job as a taxi driver. This allowed me to move my hands and feet on the job. I worked as a taxi driver for 35 years and retired in 2013.

51. While it's difficult to say, it may have been that I could have had a better job if I did not have Haemophilia or HCV.

Section 6. Treatment/Care/Support

52. I do not think that I faced any major difficulties in accessing and receiving treatment for both Haemophilia and HCV.

53. As I have already explained, on one occasion Dr Winter refused to give me Factor VIII treatment based on cost. However, this only occurred on one occasion. I have otherwise always been offered whatever was available in the market at the time as treatment for both Haemophilia and HCV.

54. When I was told that I had been infected with HCV, I was not offered any counselling. Even when I told Dr Winter that I was feeling depressed during the course of my treatment for HCV, I was never offered any psychological support. However, I am not sure if I would have used those services at the time either had they been offered to me.

Section 7. Financial Assistance

55. In 2004, I was offered money from the Skipton Fund. I received £20,000 as a lump sum and was told that if I died as a result of HCV, my beneficiaries would receive an additional £25,000 each. This was the first time money was offered to me. I thought I was receiving the money as compensation for being infected with HCV through Factor VIII treatment however, the Skipton Fund were very careful in the way they worded why money was provided to

me. They said that the money I was provided with was not compensation. I was very confused and cannot think why else they would have provided me with that money.

56. I do recall that by that time, people were referring to the issue as 'infected blood'. When I received money from the Skipton Fund, there was no mention of any on-going payments. I was under the impression that it would be the only money I would receive so my wife and I kept that money for a long time as savings for our retirement.

57. In 2016 I then received a further payment from the Skipton Fund although its name had changed to the England Infected Blood Support Scheme (EIBSS). I received £3,500 around Christmas time of 2016, which included £500 for heating expenses.

58. In 2017 I received £4,500, which was paid quarterly. In 2018 I received an additional £245 per month for heating expenses throughout the year.

59. The EIBSS have maintained that this money is not compensation and that these payments to me will now continue for life. As far as I am aware there are no conditions attached to the money I am receiving. On top of these payments, the EIBSS have also informed me that they can provide me with money for certain things if my wife and I require it, such as money for car repair.

60. While I received the lump sum payments from the Skipton Fund and now the EIBSS fairly easily, it was much more difficult to access the monthly top up payments that I am now receiving. The paperwork involved was complex and difficult to understand. From the first correspondence my wife and I received from the EIBSS, the form attached made it look as though I would not be eligible to apply for monthly top up payments.

61. When I mentioned it to my brother, he suggested that I pursue it as he said that I should be eligible. My wife and I then requested further forms and

information from the EIBSS. We received multiples forms and were told that I was not eligible for the top up payments initially. It took further persistence and correspondence to receive the right form and make sense of it. After receiving the correct form I realised that I was eligible to apply for top up payments.

62. Completing the form to apply for top up payments was also difficult. The form was hard to understand, as there were a lot of medical questions. I struggled to complete the form.

63. Overall, accessing the top up payments was not easy. I believe that there were obstacles in place to prevent my wife and I from getting that money. If my wife and I had accepted the first form and letter we had received from the EIBSS, we would not have realised that we were eligible for top up payments and would not have been able to access that money.

64. I am also of the view that the money that I am now receiving has come at a very late time for my wife and I. We should have been provided with financial assistance much sooner.

Section 8. Other Issues

65. I have a younger brother who is now 59. His name is Raymond Edge and he is also a Haemophiliac. He also received treatment under Dr Sterndale and then Dr Winter. He was also infected with HCV and received treatment for it. I remember that he kept the treatment for HCV in his fridge as he injected himself with the treatment rather than going to hospital for it.

66. My brother and I did not really talk about haemophilia or the HCV we were both infected with. When we both received treatment for HCV I think we just mentioned it to each other in passing.

67. With regards to the treatment I was offered for HCV when I was first informed that I had HCV, I am confused as to how that treatment was

available so quickly. As far as I am aware, Interferon was only introduced as treatment around the same time that I was told that I had HCV. In my view, there did not seem to have been enough time for them to have conducted clinical trials for the treatment. That was one of the reasons why I declined the treatment when it was initially offered to me.

Statement of Truth

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

Signed **GRO-C**

Dated 1st April 2019