

Witness Name: Raymond Frederick Edge

Statement No: WITN0408001

Exhibits: Nil

Dated: 25<sup>th</sup> January 2019

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF RAYMOND FREDERICK EDGE**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 November 2018.

I, Raymond Frederick Edge, will say as follows: -

#### Section 1. Introduction

1. My name is Raymond Frederick Edge. My date of birth is GRO-C 1959 and my address is known to the Inquiry. I am a retired British Telecom Engineer. My wife and I have been married for 32 years and we have two children together.
2. I intend to speak about my infection with the Hepatitis C virus (HCV), which I contracted as a result of being given contaminated blood products to treat my mild Haemophilia A.
3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it had on my life.
4. 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. My wife assists me.

## **Section 2. How Infected**

5. My elder brother, Ron and I both have a Haemophilia disorder. He always had problems with bleeding and our mother was accused of beating him as a child because of his bruising.
6. Our mother was raised by her aunts, so there was no knowledge of Haemophilia being in the family history. They were vaguely aware of an uncle who used to bleed, but they had no idea it could be genetic.
7. I did not think I was any different to other children until around the age of 7 when I fell off my bike. This was the first issue I had, which was more of an internal bleed.
8. I have always loved playing football, but it led to conflict with my health condition. Despite suffering with mild Haemophilia A, I used to play football regularly at the weekends. Knocks and bashes during the game meant that I often required treatment for bleeds into the thighs and knees.
9. As a boy I was seen by Dr Sterndale at Margate Hospital, he was old fashioned and not very endearing. The Haemophilia department at the time was in a separate building to the main hospital.
10. After a bleed or a knock, I would receive what I described as 'sludge' at hospital, a brown plasma product. I do not know what it was known as medically, but it was stored in a plastic bag and administered through my arm.
11. In the 1970s there were not enough ambulances to take you to hospital if you had a bleed. Dad would always drive my brother and I to Margate, depending on how bad it was. When you grow up with Haemophilia you learn how to manage your condition and know when to go to hospital.
12. I had one particularly bad bleed during a football game in my late teens. Another player trod on my calf muscle and it exploded, it doubled in size. I spent 6 weeks in Margate Hospital where my leg was elevated. There was no physio back then, but I remember being told that I could go home if I was able to walk to the end of the

corridor. I was unable to push my heel down, so tiptoed. The matron was very strict and forced me to walk properly, it was painful but it needed to be done.

13. I recall Dr Sterndale saying he would stop my treatment if I kept up playing football and that I should take up swimming instead, but I never wanted to. I didn't want to give in and loose my football, which was very important to me.
14. Home treatment was also suggested at one point when I was a child, but we only had a small fridge at home with no space to store it. Also, my parents didn't want to take responsibility for administering the treatment, so the proposal was rejected. This may have been a lifesaver for me.
15. I did have a blood transfusion when I was very young, although I do not recall exactly when. I still have the scars on my feet.
16. Dr Mark Winter took over as the Haemophilia consultant after Dr Sterndale retired in 1984. He came in at the point when everything surrounding AIDS rose to the fore, so perhaps Dr Sterndale knew what was to come. His clinic was in the main part of the hospital, which was nicer. Around this time I met my wife and everything was looking positive going forward.
17. The first time I had an inclination of something being wrong was over Christmas 1985. For a number of days I experienced very intense stomach pains, and was then admitted to the William Harvey Hospital. I was expected to be in over Christmas, but was discharged beforehand. The only feedback I was given was that I had too much protein in my blood, and perhaps I had eaten too many mince pies and cream. Nothing more was said, there was no follow up, and in my opinion they never got to the bottom of what caused the pain.
18. After two years of living together, my wife and I decided to buy a house in 1986. As part of the endowment mortgage, I had to take out a life insurance policy and a medical assessment was involved. I did not think anything of it, but it turned out to be an AIDS test. I was sent to either Margate or Canterbury Hospital, and the test was carried out independently from the Haemophilia department.

19. I recall waiting in the corridor on my own, when two people wearing surgical greens, masks, mortuary apron and rubber gloves approached me. I wondered what they were going to do, but they only took blood. I remember thinking if they were dressed like that to take my blood, what was inside of me, but I made no connection between AIDS and infected blood.
20. In my mind, AIDS was something that gay people had or those who were sexually promiscuous. I had sexual relations prior to my wife, but not that many, so I did not see the virus coming from that direction. I merely thought the test was necessary because of the Haemophilia, without contemplating it could be in the blood products I used.
21. I had to wait a couple of months for the test results, and it was an anxious time. The insurance company stated I was all clear, and we went on to buy our house in April 1986.
22. In the early 90s Dr Winter called me in for an appointment. By this point he had a new clinic at Canterbury Hospital. Whilst in his office, he informed me that I had contracted Hepatitis C (HCV) through infected blood products. He was unable to isolate the product that was contaminated. At this stage he was unaware of the variant, so there would be another blood test to determine this. He went on to explain that if it was either Hepatitis A or C the outcome would not be good, and that B would be the best outcome. Later on I was provided more information about the variants, and if I had Hepatitis A a biopsy would be necessary.
23. I did not know what to think of the diagnosis. I was unsure of what HCV exactly was, the effect it would have and how long I would live. I asked Dr Winter what would happen next, and his advice was to wait on the research into new treatments. I found that he was a cautious consultant in a good way; he bred faith in to you and was compassionate and caring as a doctor should be.
24. The second blood test confirmed that I had Hepatitis C, genotype 2B.
25. There was little information known about HCV at the time, but I do feel that Dr Winter was very honest. He said that I should be careful with

blood on blood contact, have a separate toothbrush and to wear condoms.

26. I do not remember being told that I was being tested for HCV, but they were always taking blood at the department to monitor my factor levels. Presumably it was detected during one of these routine blood tests.
27. Even after the HCV was discovered, I was told the Haemophilia department was very low on recombinant Factor 8 and that it would be kept for the children. If I needed treatment for a bleed, they would use the old products. The following year all Haemophilia patients moved on to the recombinant.

### **Section 3. Other Infections**

28. I do not believe that as a result of being given infected blood products I have contracted any infection other than HCV. Although I remember that I did receive a letter from Dr Winter informing me that I had an additional risk of getting vCJD.
29. As mentioned before, I was tested for HIV but it was a negative result.

### **Section 4. Consent**

30. I have been asked if I believe that I have ever been treated or testing without my knowledge or consent and the answer is no. I have always consented to Haemophilia treatment. Although I was unaware they were testing for HCV, I knew blood was consistently taken to monitor factor levels.
31. I do not believe I have been treated without being given full information. Dr Winter explained everything to the best of his knowledge.

## Section 5. Impact

32. It makes me feel sick to think I was infected with HCV through blood products intended to treat Haemophilia. I later found out from Dr Winter that he lost about 50% of his clinic to HIV, so I do count myself lucky. I always felt it could have been worse, but it was still a bombshell to be told I had HCV.
33. Since the infection I have become a lot more withdrawn, reflective and quieter than I was. Depression has been there at points, and there was a period when I was particularly insular.
34. Before the treatment started, I was worried and concerned about what was to come, especially as little was known about the virus. I felt as though I was walking one step into the dark every day.
35. I do feel very tired and exhausted, but some of that you tend to put down as just getting older. I am often lethargic and will have to lie down.
36. For some time I have had a stitch type pain in my side, but it has worsened with time.
37. I have always tried to keep myself fit and active, and did have a gym membership whilst I was working. As such there was a time when I would look forward to the gym, but I now do not like the prospect of using energy to feel even more tired.
38. I also suffer with 'brain fog' from time to time, and sometimes find it hard to express myself and concentrate.
39. Despite liver function tests being fine, my liver is probably not in a good state and I do experience aches and pains. I am not aware how badly it is affected, although I have not been diagnosed with liver failure or cirrhosis.
40. Several years elapsed before I commenced treatment in 2002. As I waited so long, there was concern that my liver may have been too badly damaged for the treatment to work. Despite the 60% chance of success, I decided to follow the advised course of treatment. I self-administered two interferon injections a day and took ribavirin tablets, for a period of 6 months.

41. I was very fatigued, tired and suffered with blinding headaches throughout the treatment.
42. I finished in the treatment in the November and went back to work. Around 6 months after I received the news that the HCV had cleared, but that I would be monitored and tested every 6 months.
43. I never researched any alternative treatments, as I trusted Dr Winter completely. He was high up on the medical boards and had a strong interest in his Haemophilia patients. He treated me as a young consultant right up until his retirement.
44. I am still under Canterbury hospital but am seen by a number of consultants. The check ups have decreased from every 6 months to every year. I have fewer bleeds now. Stupidly, I cut my head recently and I had to attend the A&E. We arrived at 5.30am and came out at 2pm; I was given Factor 8 and Steri-Strips.
45. Dr Winter introduced physiotherapy for his Haemophilia patients, and I continue to have appointments a couple of times a year.
46. I have found that medical treatment has always been patchy anyway because of the Haemophilia, but after the HCV diagnosis it became worse. I have to always declare that I was infected with HCV despite the fact that it has cleared.
47. Dental treatment is a nightmare, and I have had to become a patient person. I was always admitted to hospital for any treatment including extractions, probably because no dentist would take me on. Appointments would always be cancelled at short notice due to demand.
48. I later joined my wife's private surgery and told them of my medical background. They are cautious but I feel fortunate that they have not been negative towards me.
49. Despite building up levels of Factor 8 beforehand, I still struggle with extractions. After one procedure at the private dentist, the bleeding persisted through the night and I was swallowing clots of blood. Following this, I had another extraction at the William Harvey Hospital. They changed the method and stitched it after, this worked much better.

50. Recently I was referred from the optician to the eye clinic in Haysbank Ashford, as my left eyelid needed a tuck. As I was going to be cut, I mentioned about Haemophilia and HCV. I went backwards and forwards about the treatment, but on my last visit to the clinic the specialist did not want to carry it out, and abruptly decided the minor surgery was not necessary. His answer was next time I have an eye test, instruct the optician to tape the eyelid.
51. I have never declared I was tested for HIV because of the stigma.
52. Not long after the test I had a hospital stay, and the guy in the bed next to me was a Haemophiliac dying of HIV. I assumed he was gay at first, but we had a conversation where I found out his Haemophilia consultant was Dr Winter. Everything hit home, and that could have been me. This was around the mid 1990s and prior to the HCV diagnosis. I remember thinking I was free from it all, not knowing what was to come later.
53. I feel as though I have always felt stigma around the Haemophilia. I played football to fit in and be as normal as possible, rather than being insular. There was a lot of pressure piled on for me to stop football, as I said earlier, I felt as though it was something I needed to continue.
54. I went from 11 a side to 5 a side as I got older. It's meant to be non-contact but I did have a few bleeds from time to time.
55. My whole family was private about Haemophilia, and no one spoke about it as if it was a dirty secret. I have continued to keep it under the radar so only close family and friends know. I never once told anyone I played football with, and only spoke about it with my wife after our engagement.
56. I also kept quiet about Haemophilia in relation to jobs and other activities. I joined the TA but did not disclose my condition because I thought it would prevent me from being seen as normal. I was always slightly different at school, so did not want this to continue. I did the same with BT and did not declare anything on the medical assessment. I later joined the Royal Signals with other BT colleagues and did not mention anything then either.



57. Although HCV had no impact on education, Haemophilia certainly did. I had a number of bleeds due to punching at kicking at secondary school, so the teachers made it aware to the class that I was slightly different. They took further measures to manage my condition, and sports became an issue. I was made to do cross-country running more than anything else, which I hated.
58. My parents pushed me into an office job because of the Haemophilia, my first job being a costing clerk. I did not like the work at all so shortly left. I then worked on the railways, and then spent a period of time working in the South of France. When I came back I found it hard to get work, but through the TA others suggested I apply for BT.
59. Once I was informed treatment would commence, I wrote a letter to BT explaining my Haemophilia condition, how I had contracted HCV via contaminated blood products and that I would need some time off. I was paid for the 6 months I took off, but missed out on overtime. BT were very good about allowing me the time off.
60. I started working as a construction joiner for BT in December 1987, but they only became aware of my Haemophilia after this letter. They did become concerned about my use of knives in the working environment, and I had a couple of managerial visits when I went back to work. I could understand why they were taking such measures, but I had been doing the job for years without any problems. They were not nasty in any way, just trying to work around my condition. My working practice was not altered, but the management ensured health and safety was prioritised.
61. In recent years my job became a lot more difficult. I was getting tired quickly and there was an increased workload. I decided to retire in February 2018 at the age of 59. I always wanted to work until I was 60, but it would have been hard to continue. Copper network cabling involved climbing down manholes and carrying heavy machinery. Driving home after a day of manual work was always the worst part, and the trackers on the van could detect I was stopping by the side of the road due to tiredness. My working day was half 7 to half 3, so I

would come home and sleep straightway on the sofa for a couple of hours. It would drive my wife mad.

62. I do receive a BT pension, but due to retiring early it is a reduced amount. This actually worked in my favour for the Skipton Fund, as it placed me under the qualifying income.
63. We told the children that I was ill, but never made a big deal about the HCV. I feel as though they never understood the full implications of the virus because they were so young at the time, and only at primary school when I received treatment. They have always seen me in the same light, so it has not impacted them negatively. As a couple, my wife and I have always been light hearted about Haemophilia, but my daughter is concerned she may be a carrier.
64. After the diagnosis I had to be extremely careful with blood on blood contact with the family, and not to cross contaminate. I bought a red toothbrush, as it was a danger for the family to use.
65. My wife has found my infection with HCV particularly hard because she works for the blood service. She is also unable to give blood, she has had to declare that her partner was given contaminated blood products.
66. On long haul family holidays I would bring a supply of Factor 8, along with a doctors note. We did have some at home at one stage but this was only whilst I participated in 5 a side football.

#### Section 6. Treatment/Care/Support

67. I have had no issues in receiving treatment for HCV. Although the NHS infected me with the virus, I have experienced good care and everyone in that community has been there to support me.
68. I do not recall being offered counselling when I was diagnosed with HCV.

## **Section 7. Financial Assistance**

- 69. Around 2003, Dr Winter mentioned about compensation during an appointment. He went on to explain that the payment was for being infected with HCV through contaminated blood products. I was given £20,000 after signing a disclaimer prohibiting further entitlement.
- 70. I also made an application to the Skipton Fund, which was accepted. Initially I received monthly payments of £300, but since I retired I now receive an additional £200 each month.
- 71. Each year I am given a winter fuel allowance in the region of £500.
- 72. I never faced any difficulties in applying for and obtaining financial assistance.

## **Section 8. Other Issues**

- 73. In connection with the Haemophilia Society, I wrote to my local MP GRO-C to raise the awareness of infected blood. Around the time of my treatment, I also went up to Westminster with a petition of names.
- 74. I did attend a seminar run by Bayer with my wife, on having haemophilia in old age. There were only about 20 attendees, but most people had been infected with HIV and HCV. They were clearly upset and bitter about being given infected blood products.
- 75. The Inquiry has been a long time coming and I hope that the truth will prevail and those responsible for allowing contaminated blood to enter the transfusion and blood product system will be identified and held to be accountable for this disaster.
- 76. I have been asked if I would be willing to attend the hearings in person to give my evidence. The answer to this is yes.

**Statement of Truth**

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

Signed

GRO-C

Dated

25:01:19.