Witness Name: Doreen McCleave
Statement No.: WITN0348001
Exhibits: Nil
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DOREEN McCLEAVE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 February 2019.

I, Doreen McCleave, will say as follows: -

Section 1. Introduction

1. My name is name is Doreen McCleave. My date of birth is GRO-C 1950 and my address is known to the Inquiry. I am widowed housewife. I have 4 children and 11 grandchildren.

2. I intend to speak about my late husband Gerard McCleave (GRO-C 1953 – 19 April 2016). He had been infected with the Hepatitis C virus ("HCV"), as a result of being given infected blood through a blood transfusion.

3. In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

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 daughter Lynsay Mulcahy assists me.

Section 2. How Infected

5. In 1969 at the age of 15 my husband was shot. It was the first night of the troubles in Belfast, and he had been at the wrong place at the wrong time.

6. He was taken to the Royal Victoria Hospital for treatment where he received a blood transfusion. He recovered well.

7. Everything was fine until he was in his 30s and he started to experience abnormal flue like symptoms. He was not eating, lost a lot of weight and suffered with fatigue and severe headaches.

8. When his blood was tested the doctor explained his liver levels were high, so not to touch alcohol. He did not have a drop of alcohol after this and a further test was taken later on. The liver levels had remained the same, and this is when they detected the HCV. My husband was not told they were testing for it.

9. Dr Downy at Crocus Street Surgery confirmed the diagnosis of HCV but not much information was provided. I imagine he would not have known an awful lot about the virus at that point anyway, as Hepatitis C was only just coming into light.

10. After the diagnosis he went to the hospital to watch an information video. He was told how the infection could be passed on, so was very careful with blood contact at home and if he had a cut. He was extremely fearful of passing the infection onto the family.

11. We were unable to retrieve his medical records from when my husband received the transfusion. The Royal Victoria Hospital stated they were

moved to another storage facility and later destroyed. Records in relation to his diagnosis and treatment for the HCV should be held by his GP.

12. He had no other blood transfusions and had no tattoos or piercings. Prior to the diagnosis he was a healthy, active man.

Section 3. Other Infections

13. As far as I am aware my husband did not contract any other infections as a result of being given a blood transfusion.

14. It was never mentioned that he should be tested for any other infections.

Section 4. Consent

15. My husband always consented to being treated and tested. However, when diagnosed with the HCV, he was not aware his blood was taken to test for that virus.

16. Information was not always passed onto the family unless specifically asked for. My daughter had to put in a request to speak with the consultant about a second liver transplant. It should not be up to family members to seek information. Unfortunately in my husband's case most of the information was provided too late.

17. Whilst at Kings College Hospital for his last assessment, he provided consent for his biopsies to be used for the purposes of research. He even allowed a group of student doctors to be present for the assessment, as he felt that they should be aware of the symptoms. They were shocked about the state of his legs and the extent of the bruising.

Section 5. Impact

18. After the diagnosis he was monitored and blood would be taken every couple of months at hospital to check the liver levels. All care was directed by the Royal Victoria Hospital Belfast, under Dr Callender and later by Dr McDougall. He was regularly in and out of hospital for tests to detect any other symptoms to treat.

19. My husband seemed to get worse as the years progressed. His energy levels dropped and he was always tired. The chronic fatigue meant he would often be asleep on the sofa wrapped in blankets and with a hot water bottle, despite the heating being on.

20. His health rapidly deteriorated and he suffered with swollen legs, joint pain and itchy skin as a result of the infection. He also experienced kidney problems, including stones and would pass blood when going to the toilet. As the case for all other medical symptoms, we were told this was in relation to the HCV.

21. He bruised very easily. On one particular day he woke up and his leg was completely black. He was in agony so I drove him straight to casualty. I had to drive really slowly as he was in so much pain. The doctors were unsure what it was, but it was put down to the HCV.

22. My husband took everything as part and parcel of the HCV and dealt with the symptoms as nothing could be done. He just had to live with it, as the HCV was incurable. He was registered disabled and had a blue parking badge.

23. His mood was certainly affected by the virus and at times he was aggressive. This worsened as his health deteriorated.

24. Treatment to clear the HCV was offered but my husband was told there was not a high probability it would not work. The medication was still

relativity new and experimental, but he was the type of man who would try anything to help.

25. He took ribavirin in combination with injections of interferon administered to the stomach. There was no side effect to the treatment but it had no positive outcome, once he stopped the medication the virus returned.

26. He developed cancer of the nose as a result of the medication he was taking. It was removed but he was left with a bad scar running down the middle of his nose.

27. My husband also researched other ways to help the liver and started taking milk thistle tablets. He was prepared to try anything to improve his condition.

28. A liver biopsy was taken and confirmed that he required a transplant. He was taken via air ambulance to Kings College Hospital London for the procedure, and it was undertaken on the 17 March 2004. He was informed it would last 10 years.

29. He was kept in for 10 days before coming back to the Royal Victoria Hospital for a number of weeks to be monitored.

30. Tacrolimus was prescribed to prevent the new liver from being rejected. They had to be taken at specific times during the day so his life became very scheduled.

31. 6 weeks after the procedure his skin became extremely itchy and his body started to reject the liver. He was admitted back into hospital where it was discovered that the HCV had infected the new liver.

32. The new liver was not completely rejected but it was also infected with HCV. It certainly gave him a new lease of life and another 13 years, but the problems exacerbated after the transplant.

33. My husband suffered a lifetime of illnesses due to the HCV and it impacted his life every day.

34. During the last few months he deteriorated rapidly and he was constantly in and out of hospital. It was a stressful time for the whole family.

35. It felt as though everything was left until the last minute by the hospital. By the time he was sent over for an assessment at Kings College Hospital he was in a wheelchair. His legs were swollen and full of fluid, so he should not have been on a regular flight. Unlike the stomach, the legs are unable to be drained so there was nothing that could be done. He required the disability aid to board the plane, as he had no mobility. If he had not had the assistance of my daughter and I he would have been unable to go. At this point he was also suffering with renal failure.

36. Everything in regard to accommodation and transport arrangements for the assessment was left to my daughter, the family and I. We received no support from the hospital.

37. Once he got to Kings his condition deteriorated further and instead of assessing him they ended up treating him, including for the renal failure. During this time his mouth started to swell up and bleed, so he was unable to eat. He was meant to be there for 3 days but was kept in for over a week before an air ambulance transported him back to the Royal Victoria Hospital on 22 February 2016.

38. The assessment should have been carried out months prior to when it was. They knew the shelf-life of his previous liver was 10 years. I cannot understand why it was left so long when the liver unit constantly monitored him and carried out scans. He never missed any appointment, and the symptoms should have raised a red flag for an earlier assessment.

39. He was in the Royal Victoria Hospital for 8 weeks during which time his condition worsened further. It was a horrendous period of time for all of us. He was back on the liver transplant list but not on priority. His heart had to be tested before he could be sent back to London. None of us wanted to give up because of the possibility of a transplant.

40. The liver was unable to filter out any toxins, so he experienced delirium and confusion. At times he did not know where he was. His body also went a yellowy green colour.

41. My husband received no one to one care when he should have. He had a drip up his nose but kept pulling it out as he became agitated. At one minute he would be aware of what was happening, but then would not. He was constantly afraid that he was going to die.

42. As a family we spent a great amount of time at the hospital because my husband did not have sufficient support. We were unable to stay overnight with him and told we could only attend to him during visiting hours. Despite this we still continued to visit outside these hours. My son would go down in the morning to make sure he ate, and get him out of bed to walk up and down the ward.

43. The hospital staff kept talking about tube feeding because he was not eating, but the nutritionist never came to see him.

44. One night he inhaled blood into his lungs, which could have been prevented had he been tube fed. This progressed into pneumonia and he was resuscitated when his heart stopped. He was taken to an intensive care unit and at that point we thought that was it.

45. The following day I accompanied my husband and 2 doctors to Kings College Hospital London. They were still going to carry out the transplant if he pulled through. Unfortunately they were unable to get his lungs to function because of the pneumonia, and my husband died on 19 April

2016. Liver failure as a consequence of HCV is the cause of death on his death certificate.

46. My son stayed in London to register his father's death, and this was particularly stressful for him. In Northern Ireland you are buried within a couple of days whereas in London a couple of weeks are the norm, so there was no push for the death to be registered quickly.

47. Due to the infection with HCV they refused to embalm my husband's body, so he started to deteriorate. Repatriation back to Northern Ireland was also stressful.

48. Throughout his illness my husband always tried as best as he could, and when he passed away the GP phoned to say he had not seen someone handle an illness with such dignity.

49. My husband was a very social man and would enjoy going out with friends. All of this stopped, as he was virtually housebound for the last 5 years of his life. He had difficulty eating and even had to go home at a family Christmas dinner.

50. As a family we were unable to go on holiday because he was uninsurable for travel. There was always a fear that something could happen whilst away from the home.

51. There continues to be an impact on our family life. Some of our grandchildren have lost out on knowing their grandfather, the youngest being only 1 when he died. He is missed greatly and he died too young at the age of 62.

52. My husband was a very private person and kept a lot to himself, but there was no stigma at all within the family or circle of friends. When you mention problems with the liver people tend to assume it is alcohol

related, so we felt it was important to state the implications were brought on from HCV, as a result of a blood transfusion.

53. He was very particular about his teeth and experienced bleeding gums as a result of the HCV, so did explain about the infection to his dentist. She was very good and there were no problems at all with receiving treatment.

54. Up until the diagnosis he was a regular blood donor, so he was concerned about how many people he infected secondary with HCV. The doctor at the Royal Victoria Hospital was made aware but I am unsure what action was taken.

55. Prior to the HCV diagnosis my husband worked as a steel erector, but due to the infection he had to stop work. This created a huge financial impact for our family, where we had to rely on benefits for every day living. The amount of money received was not sufficient, and compensation payments were not received in the early days of his diagnosis.

56. As I widow I am still impacted financially by my husband's infection with HCV. He was uninsurable so there was no life insurance policy attached to our mortgage, and I was left with repayments after his death. All financial assistance stopped after my husband passed away, so I had no income to pay off the mortgage except a state pension. My daughter contacted the lender to create a more manageable payment.

Section 6. Treatment/Care/Support

57. I have been asked if we ever received any psychological support or counselling, my husband and I were never offered any support.

58. There were a couple of group sessions, which he attended but these were more as a support for liver transplant patients in general.

59. My husband did not face any difficulties or obstacles in obtaining treatment in consequence of being infected with HCV. Only as I have mentioned whereby everything towards the end seemed to be left until it was at a critical point.

60. Unfortunately there was no support or information readily available. We relied on our own research using the Internet.

Section 7. Financial Assistance

61. A nurse at the liver clinic told my husband about the Skipton Fund. He went home to look into the support offered and then registered.

62. The application process was not difficult and he was provided with supporting documents from the hospital as evidence.

63. Both stage one and stage two payments were granted. I cannot recall if any conditions were attached to the payments, but I do not think so.

64. During the last year to 6 months of his life, my husband also received monthly payments from Skipton. It was in the region of £1000 a month. This support was not received for long as it stopped as soon as he passed away. His disability payments also stopped at this point.

65. The Caxton Foundation provided grants for items when my husband was alive and he used their support a few times.

66. They also provided a monthly income for myself, which has now been transferred to the BSO on behalf of the health trust. I currently receive £166 a month. It helps but it is not enough.

67. There is no option to receive grants from the BSO, as the guidelines for entitlement are very specific.

68. The financial assistance received was not an awful lot when you consider the impact HCV had on my husband's life and on us as a family.

Section 8. Other Issues

69. Just a public apology for the contaminated blood scandal is not acceptable. I am shocked to find out that people knew where the blood was coming from and willing to pay prisoners and drug addicts. It is ludicrous. You never would think these things actually happen.

70. What happened to my husband and many others has impacted my trust of the NHS. I am now very aware that information is not always divulged and health professionals are not always right.

71. I find it incredible that my husband needed to travel to London for assessment prior to receiving a liver transplant. Surely such a facility should be available somewhere in the whole of Northern Ireland? I am sure that undertaking such a journey can only be detrimental to his condition.

72. I am not a blood donor.

73. From spending so much time in hospital with my husband I can no longer face to go in them, even to visit family members.

Statement of Truth

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

Signed GRO-C

Dated 19\5\2019.