Witness Name: Patricia Warner
Statement No.: WITN1994001
Exhibits: WITN1994002 – WITN1994025
Dated: 7 June 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PATRICIA WARNER

Section 1. Introduction

1. My name is Patricia Warner and my date of birth is GRO-C 1951. My address is known to the Inquiry.

2. I am writing this statement in memory of my late husband Peter Mycol Austyn Warner.

Section 2. How Affected

3. Peter was infected with HCV from multiple infusions of the blood product immunoglobulin at Norfolk and Norwich University Hospital.

4. I met Peter in 1967 when I was 16 years old, and we married in 1969.

5. In 1974, Peter was diagnosed with hypergammaglobulinemia, which is a deficiency of immunoglobulin in one's blood. To treat this, he was put on a trial of immunoglobulin replacement therapy in December 1974 which

required him to receive regular intramuscular injections of immunoglobulin **WITN1994002**. The blood product used in this trial was supplied by the Regional Immunology Laboratory at the East Birmingham Hospital **WITN1994003.** He remained on this treatment from 1974 to April 1985.

6. In early 1985, Peter had three bad reactions to his injections in a short period of time, causing him nausea, vertigo and sweating. He was concerned he would have another reaction, so he went to his GP in March 1985 to ask if there was anything he could do to reduce the risk of having an adverse reaction. Following this appointment, I understand from his hospital notes that his GP wrote to his treating haematologist, Dr GRO-D, asking what options were available to Peter other than the treatment he was currently receiving **WITN1994004** .

7. Dr GRO-D wrote to immunologist Dr R A Thompson to ask for guidance about whether intravenous immunoglobulin would be available for Peter **WITN1994005.**

8. On 2 April 1985, Dr Thompson responded to Dr GRO-D as follows **WITN1994006**:

> There are intravenous preparations available commercially from Sandoz, Biotest and Cutter Laboratories among others…the preparations are not entirely free of side effects but since they are all given by slow intravenous infusion over a period of one to two hours, these are usually negligible. However, they are quite expensive and we are looking forward to the day when the Blood Products Laboratory at Elstree brings its own intravenous preparation into production.

9. Dr GRO-D then wrote back to Peter's GP saying that he had decided to put Peter on a trial of a new commercial blood product called Sandoglobulin, which was to be injected intravenously. He noted in his letter that this product was "very expensive" and that this trial had been recommended by Dr Thompson **WITN1994007**. There is no evidence of Dr GRO-D making any enquiries about the side effects or risks involved with this treatment before making the decision to give it to Peter.

10. In May 1985, Peter started on this new trial of Sandoglobulin.

11. Before this, Peter had been a very active man and a bit of a daredevil. But after he started receiving the Sandoglobulin treatment, he began to feel very poorly. He was very tired and spent all of his time laying on the sofa or sleeping. He couldn't go out in the garden as he liked to or do much of anything. He still tried to make an effort with the children, but they understood he was ill and couldn't play as actively as he used to.

12. On several occasions, he brought his illness and lethargy to the attention of his haematologists during routine appointments. On 11 November 1986 it is noted that he that he felt "run down" and would prefer not to have his Sandoglobulin treatment that day as he felt he may be having a reaction to it **WITN1994008**. Dr GRO-D agreed to postpone his infusion to the following week, but nothing was done to investigate the reaction he was having. In January 1989, it was noted that he had developed a flu like illness with a fever and productive cough **WITN1994009**.

13. Peter also started becoming jaundiced. In early 1991, the nurse who administered his treatment told him that his skin was very yellow, and when I asked her what the cause of this was, she said it would need to be investigated.

14. These investigations led to Peter being diagnosed with hepatitis, although he was not yet tested for HCV. His hospital notes from 7 March 1991 say: "He has an acute hepatitis of unknown cause..Sandoglobulin is treated so that I would be surprised if he had acquired infection from this". **WITN1994010**.

15. On 30 April 1991, it is noted that he was "feeling 80% better but jaundice still present clinically" and that there was "no explanation for his predominately hepatocellular disorder" **WITN1994011** and on 9 May 1991, he is noted as being in "recovery from acute hepatitis" **WITN1994012.**

16. On 5 July 1991, it was noted at his appointment with Dr GRO-D that he continued to be jaundiced, his liver function was abnormal, and that he had noticed itching with pale stools and dark urine for two or three days after his Sandoglobulin infusion. **WITN1994013**. Peter was tested for HCV that day and this came back positive **WITN1994014**. Dr GRO-D provided him with information about HCV, including the risks of infecting others, and said he had probably contracted from "a bad infusion" of Sandoglobulin. In the meantime, he tried to find out more about HCV and his prognosis from various local groups, and befriended another man with HCV who came to visit him in hospital.

17. After an appointment Peter had with Dr Fellows, Consultant Physician, on 2 August 1991, Dr Fellows noted to Dr GRO-D "I suppose it is possible that he has acquired hepatitis C passively via the Sandoglobulin but hepatitis C would be an explanation of his recent illness" **WITN1994015.**

18. On 2 October 1991 Peter was admitted to hospital for a liver biopsy. Dr Fellows noted that he was "known for Hep C (after blood transfusion probably)" and that he had no risk factors other than from globulin treatment **WITN1994016.**

19. On 18 October 1991, Peter's biopsy results showed he had "chronic active hepatitis with piecemeal necrosis and increase in fibrous tissue" **WITN1994017**. It was suggested that he participate in a trial of interferon treatment.

20. Peter instructed solicitors in 1993 to investigate a claim for negligence arising out of his HCV infection. His solicitors informed Norfolk and Norwich Hospital that a claim was being investigated against the health authority and/or the drug company producing Sandoglobulin, and the Director of Administration at the hospital wrote to Dr GRO-D on 8 February 1993 to ask him for information about Peter's treatment that could be relevant to the claim **WITN1994018**.

21. Dr Fellows responded to Mr Drew on 11 February 1993 as follows **WITN1994019:**

> He was referred to me in March 1991 by Dr GRO-D when I made a clinical diagnosis of acute hepatitis of unknown cause. He was followed up in clinic but his liver function tests did not return to normal over the next six months and he was then admitted for a liver biopsy in October 1991. This together with serological tests confirmed a diagnosis of chronic hepatitis C infection. Treatment was instituted with alpha interferon injections three times a week and he remains under follow up demonstrating a good response of his liver inflammation to this treatment. The source of his hepatitis C infection remains unknown. He claims that it was caused by sandoglobulin. I am not in a position to confirm or refute this allegation. Hepatitis C can be transmitted by the infusion of blood or blood products but can arise in the absence of such treatment.

22. Mr Drew wrote to Dr GRO-D on 26 May 1993 asking him if he would provide a report or statement for use in the case. He noted **WITN1994020:**

> It would appear that it was the temporal association of the onset of hepatitis and the termination of the treatment without explanation which precipitated the association in the mind of Mr Warner and therefore his recourse to legal action.

23. Dr GRO-D responded as follows on 7 June 1993 **WITN1994021**:

> I first saw him in 1974 when he was referred by the chest department after they had found that he was hypogammaglobulinaemic when investigating his recurrent chest infections. I recommended a trial of gammaglobulin by weekly intramuscular injections. He seemed to benefit, getting fewer chest infections, and he continued this treatment until he voluntarily gave it up after a number of years because of unpleasant reactions. In 1985 his GP wrote to me and I sought advice from DR RA Thompson, consultant immunologist, who recommended intravenous gammaglobulin which had just then become available, as being less likely to give him reactions and to provide a higher blood level. I therefore arranged for him to receive Sandoglobulin by iv injection every three weeks given as a day case and he started this treatment in 1985. In February 1991 he became unwell and jaundiced. I referred him to Dr Ian Fellows who came to a diagnosis of Hepatitis C. I do not know whether this was related to his gammaglobulin treatment or not, and I do not know any way of finding out.

24. I do not remember exactly what happened after this, but in the end we had to abandon this legal case because of lack of funds.

Section 3. Other Infections

25. Peter was infected with HCV only. He tested negative for Hepatitis B.

Section 4. Consent

26. I do not think that Peter was treated or tested without his consent. However, he was not given full information about the risks of being treated intravenously with commercial product sourced from human plasma and so did not consent to this. I believe that if Peter had been told about the risk of infection from Sandoglobulin, he would not have taken it and would have either waited for it to become available on the NHS or considered other treatment options.

Section 5. Impact

27. Shortly after Peter's diagnosis, he was able to participate in a trial of interferon treatment. This required him to have injections three times a week for nearly two years, from October 1991 to November 1993. **WITN1994022.**

28. During the interferon treatment, Peter suffered serious side effects. He was tired and lethargic, and felt like he couldn't do anything. He used to say he thought he would be better off dead at times because he had no life. The treatment seemed to go on for years, and he felt cheated that he had been having Sandogloublin infusions every two weeks for so long and one bottle was wrong that changed his life forever.

29. The treatment also caused other complications. He had chest infections so often that he would phone up the GP and say, "I've got an infection again", and they would immediately prescribe another antibiotic without even having to see him because of how accustomed they were to his chest

infections. He developed a problem with his jaw which meant he couldn't open it properly.

30. The effects of the treatment on him were difficult for our children, as it was hard for them to see their dad this way. The older two children helped out with him when they could because they were old enough to understand he was getting treatment for an illness and couldn't be his old self anymore. The youngest daughter was too young to understand, but as long as he was there with her she was okay. He was still a silly grandad and put on a brave face, but when he was on his own at night he would collapse on the sofa.

31. After finishing the interferon treatment, Peter's liver function returned to closer to normal and he tested PCR negative for HCV **WITN1994023.**

32. I note that there is an entry in his hospital records from May 1995 which notes that he was "currently on SNBTS Ig [immunoglobulin]" **WITN1994024.** This means that at some point he had been switched from Sandoglobulin, the commercial product, to immunoglobulin produced by the Scottish National Blood Transfusion Service. If this presumably safer product was available, I would like to know why he was not moved to this product in 1985 instead of Sandoglobulin.

33. I don't remember being specifically told when Peter was transferred to the Scottish product. There were a few times when his product was changed but I don't know what information was given to him about it: Peter always assumed it was the hospital trying to save money on the treatment and just hoped he wouldn't have any reactions to the new one.

34. He continued to be monitored regularly and by 1997, it was noted that he had cleared the virus and no further treatment was necessary other than checking his liver function and testing him for HCV once a year **WITN1994025.**

35. I was absolutely amazed that he had successfully fought the virus. He said it wasn't going to get him, and it didn't. He was feeling better and was able to go back to work. However, he wasn't quite the same person. He didn't seem to have the same gusto that he had before. He tried to be the same as he was before, but he couldn't stop worrying each time he had his infusion that it would happen again. Worrying so much was totally out of character for him. He would obsessively check his eyes to see if they were yellow and ask me if he looked yellow after each infusion. But he had no other option other than to continue the infusions because if he didn't have them, he would constantly have something wrong with his chest.

36. We had a couple of friends who would not come near him after his diagnosis because of the stigma against hepatitis. One of them was confused and thought he had AIDS. We tried to explain it to him, but he said he would never come again. That hurt Peter very much.

37. Peter's social life went downhill completely. For a couple of years, we didn't have a social life except for the children. We did have some very good friends who helped when he wasn't able to do things; I wouldn't have managed without them. But before becoming ill, he was a very social person and would often go out with friends, and afterward he was not able to do this. Instead we would have friends round, rather than go out, because if he got tired he could go and lay down for a while.

38. After clearing the virus, Peter's health stayed fairly stable for a number of years. Then around 2010, he started complaining that he had chest pain and thought his heart was playing up. I told him to go to the doctor, but he said they would just give him a load of stuff and send him on his way. He had lost faith in doctors.

39. One day, he went out in the morning with the dog and called me later saying he wasn't feeling well and was going to go to the GP. I went to meet him there. The doctor said his ECG was okay and wasn't having a heart attack, gave him morphine and sent him to A&E. When he arrived, the

hospital admitted him, gave him his immunoglobulin infusion and told him he would be discharged the next day. I remember that a nurse moved him onto a trolley and he asked if he wouldn't be getting a bed. The nurse replied, "you're lucky you get this, you're not dying".

40. The next morning, the hospital phoned me and told me to come as soon as possible. He had a blood clot travelling toward his heart. We got there 20 minutes before he died. It was 22 April 2010.

41. The doctor told us that he had had lung cancer, but it was so vicious and hard to detect as it was in the upper corner of one of his lungs. They don't know if he had gone to the GP earlier about his chest symptoms, it would had been caught.

42. Peter's funeral was several weeks after he died because the post mortem took three weeks to find the cancer in order to determine his cause of death. At the time of Peter's death, our children were 28, 40 and 42. When it came to organising the funeral, our youngest daughter went into overdrive. She organised everything for me because I was numb and couldn't believe what had happened.

43. I always thought earlier in our lives that he maybe wouldn't make it to old age, but he was 64 by then and his health seemed stable. I thought he was doing well. My daughter adored him and was absolutely devastated. She decided to organise everything, and it was clear to us that she was having a breakdown. Her older brother knew he should be doing it and said "mum, I'm just letting her do it because otherwise we're going to have a problem with her." She was very poorly afterward. She lived at home with us for a year, and eventually went to work after about two or three months, but she was fragile. If you mentioned her dad she would burst into tears.

44. The older two were less seriously affected by it than our youngest daughter. They had partners and families of their own, and they had been brought up to know that their dad was ill and might not live as long as other

people. Of course, they were upset at how suddenly it seemed to happen and sad not to have him around, especially for the sake of his grandchildren. His oldest grandchildren still talk about their early memories of him, but his younger grandchildren were never able to meet him. They have been told stories about him and have pictures of him that they look at and talk about.

45. Peter worked as a self employed Area Manager for an American insurance company. His income was quite high and he managed a team. Once he started taking the interferon treatment, he couldn't do the job anymore and had to hand over the team to someone else. He didn't work at all that year. We managed on benefits and sick pay, but it was a challenge for us as we relied on his salary.

46. He felt pressured to go back after a year of treatment, but didn't go back into the management side, just as an insurance representative working fewer hours as he felt this would be less stressful. However, it got to the stage where the job was still giving him the same stress levels he had as a manager but with less pay. He was finding working even a few hours a week to be too much. He did that for a few years and then gave it up completely around 2007.

47. I then went back to work full time for the Nationwide building society. With my income and his sick benefits we got by, but we had no luxuries. We used to go on two to three holidays a year, but we never went on holiday anymore. It just made a vast difference to us. After he died I couldn't face working, so I have been retired for about 10 years.

Section 6. Treatment/Care/Support

48. Peter never faced any obstacles in obtaining his interferon treatment. He started it very soon after being diagnosed with HCV.

49. Peter was never offered any counselling in relation to his HCV and none of us were offered counselling about his illness or death.

Section 7. Financial Assistance

50. Peter received a £20,000 payment from the Skipton Fund.

51. He was approached in the hospital by another patient named GRO-C who also had HCV and informed him that they were both eligible for financial assistance. We looked into it and found he was entitled to the payment, so applied for it.

52. Although we got the money and paid off our bills in the short term, he didn't gain anything long term from it. He was still out of work and unable to earn money.

53. We have found that the Skipton payment was not nearly enough, and have kept all the paperwork in case we might be able to fight for more. The illness took his life away from him. After his diagnosis he was never the same. We had a good life beforehand, but afterward it slowly went downhill because of his intense worry that it would happen again.

54. We were told that Peter could not apply for a Stage 2 payment from the Skipton Fund because he didn't have liver cancer. I don't think this is a fair approach. Peter had serious complications from his interferon treatment, which lasted two years and caused him to lose his job. He then was plagued by worry and anxiety which seriously affected his quality of life. He did die of cancer in the end, but because it was not liver cancer we do not quality for any assistance.

Section 8. Other Issues

55. I am concerned with the length of time it has taken for the Inquiry to happen. The Government has known there was a problem for many years and not done anything about it. I believe it has taken so long because the Government did not want to pay all of the people who were infected and were hoping it would go away or some of them would no longer be alive. Peter would have been in his 70s now and it would have been lovely for him to be able to get another payment and do a few of the things he wanted to do.

56. Peter would have wanted me to spend the rest of my life comfortably as well. I had to take out a negative mortgage on the house to make sure I had enough money to live. I wish more than anything that he was still here to enjoy any payout while he still could, but as that's not possible I would like to be given financial assistance to help me cope with the effects of his illness and death on my finances.

57. There was one doctor at Norfolk and Norwich hospital who was not the nicest to Peter. He didn't understand how Peter had contracted HCV and clearly did not know much about the illness. I remember Peter and I looked at each other and raised our eyebrows because the doctor was implying Peter had been a ladies' man and caught it from someone. He was okay once we explained to him that it was from his infusions, but I feel he should have known from Peter's records or at least should not have assumed until he had the full picture.

Statement of Truth

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

Signed ... GRO-C

Dated ....07...04...21..........