Witness Name: J Carver

Statement No: WITN1141001

Exhibits: WITN1141002

Dated: November 2018

## INFECTED BLOOD INQUIRY

# FIRST WRITTEN STATEMENT OF JOAN CARVER

I, Joan Carver will say as follows:-

### Section 1: Introduction

- 1. My name is Joan Carver of GRO-C Surrey, DOB GRO-C 1930. I am the widow of Anthony 'Tony' Carver, who died on 07.05.1994. I live alone with my two dogs, Crystal and Thomas.
- Tony's death certificate is attached to this statement as "WITN1141002".
   This records the cause of death as bronchopneumonia for reasons that are discussed later in this statement. Tony was infected with HIV as a result of receiving infected blood products.
- 3. This witness statement has been prepared without the benefit of access to my late husband's medical records. I have been told that these are no longer available because he died in 1994 and the records were destroyed 10 years after his death.

## Section 2: How Affected

| 4.  | Tony was diagnosed with moderate Haemophilia A after he was shot after WWII when he was doing national service at the mail office. He was flown back to England where he received treatment.   |
|-----|--|
| 5.  | GRO-C however he did not let this affect his early life; he used to box as a hobby. He would only require treatment on demand and, as far as I know, this was not needed often.  |
| 6.  | I remember that he told me he had a tooth out at Westminster Hospital on one occasion (before we met) and that he was treated with snake venom.  |
| 7.  | Tony and I met in 1951. We married in 1952 and our first daughter Paula was born in 1953. Our other children, Deborah and Belinda, were born 1956 and 1963 respectively. We thought that haemophilia had died out in our family because we had girls but GRO-C was born with the condition.  |
| 8.  | Tony's received most of his treatment at St George's Hospital in Tooting under the care of Dr Bevan who subsequently moved to St Thomas' some time after Tony's death.   |
| 9.  | Initially Tony was treated with snake venom before moving on to cryoprecipitate. In 1983, he had a tooth removed at St Georges and in the same year, he was also treated privately at the Spire St Anthony's in Worcester Park. I do not know exactly what operation he had — only that it was something to do with "plumbing". On both occasions he was treated with Factor VIII. |
| 10. | His surgery at St Anthony's was arranged via his health insurance which he had through work (he was an area manager at Allied Lyons). I specifically remember that he had Factor VIII on that occasion because we received a copy of the bill and the Factor VIII alone cost £4,000.   |

- 11.I remember one day in 1983/4, Tony came home and told me he was being tested for HIV. The first test came back negative; however he went for a further test the following year which came back positive. Tony was told he wouldn't live more than 10 years.
- 12. We were basically told that HIV could be spread through bodily fluids, and we were not given much advice other than this.

| 13. | I was also then | tested for | or HIV by Dr | Bevan    | and I have  | never ha | d blood | test |
|-----|-----------------|------------|--------------|----------|-------------|----------|---------|------|
|     | results back so | quickly.   | Fortunately  | I tested | l negative, | G        | RO-C    |      |
|     | GRO             | )-C        |              |          |             |          |         |      |

#### Section 3: Other Infections

14. I do not know whether Tony was exposed to any other infections because I have not had access to his medical records.

#### Section 4: Consent

- 15. We were never told of any risk of being exposed to infection from blood products. When Tony was first given Factor VIII it was billed as some kind of wonder drug.
- 16.At around the time that Tony was due to have his operation at St Anthony's there had been a lot of media coverage about the risk of AIDS to haemophiliacs from American blood. Without telling Tony I made a separate appointment to see his surgeon and I told him that I only wanted Tony to have English blood products, not American ones. I remember this because the appointment cost £50.00.
- 17. Years later I had a hernia operation done by the same surgeon but at St Helier's Hospital. Tony had died by then but I said to the surgeon "that Factor VIII wasn't what I asked for was it?" He did not respond. I cannot recall his

name but I assume that it will be in my medical records and I will apply to obtain these.

## Section 5: Impact

- 18. Tony was a very level headed man, and quickly got all of his affairs in order and took out whatever insurance he could to make sure his family were looked after when he passed. He had had a good job and a reasonable pension.
- 19. He continued to work as an area manager for Allied Lyons after his diagnosis, but Tony had to retire early in 1986 because he was finding it increasingly difficult to drive and he had to drive for his job.
- 20. Tony had always been a very active man and really enjoyed his job. He was well like there and I have no doubt that had it not been for his infection, he would have continued to work for as long as physically possible as he always wanted to be busy. Even after giving up full time work I'm sure Tony would have liked to work part time just to keep himself busy, as that's the kind of man he was. He did some work with the Samaritans and belonged to the Haemophilia Society. I did a lot of crafting which helped raise money for the Society.
- 21.He loved to walk the dogs and was very passionate about his garden. Tony had a vegetable patch and was always outside looking after the garden. As he got increasingly ill, we had to get a gardener as he became unable to look after it anymore.
- 22. In the early stages of the illness Tony remained very stoic and would not talk about the infection or complain. Despite this it was clear that Tony was often very depressed. As his illness progressed he became more depressed and frustrated particularly when he could not do the things he wanted to do.

- 23. As his immune system weakened he suffered from shingles and Bell's Palsy, however he continued to stay strong and the doctors were amazed at how fast how he got over it.
- 24. In 1990 we went on the cruise to the Norwegian Fjords. We had planned to do another cruise the following year but Tony's health deteriorated and we never did.
- 25. By 1991, when Belinda got married, Tony's health had become to deteriorate and he got tired easily. In the final few years of his life, his health deteriorated rapidly. He had terrible stomach problems, lost a lot of weight and would fall over a lot. Tony became unable to concentrate and couldn't even watch the television as a result. We would constantly be in and out of hospital. At one stage Tony had the worst bed sores I had ever seen. He had these in St George's and when he was discharged home the hospital had to provide a special ripple mattress for him and the District Nurse came in regularly to treat him.
- 26. Tony was put on AZT in or about 1991 which also had horrible side effects. Tony would frequently fall over and have black outs. He was too big for me to pick up so I would have to ask my neighbours or my son-in-law for help, often in the middle of the night. At first I didn't realise that I could call an ambulance to help but later on I did call out the paramedics.
- 27. Tony and I had booked a flight to Hong Kong in 1991 to visit our daughter Deborah who was living there, however we were unable to go due to Tony's health. In the end Belinda travelled with me and her husband stayed at home with Tony.
- 28. Eventually the illness spread to his brain and at times he hallucinated. I remember on one occasion Tony telling me about the birds flying around his room. Towards the end of his life he didn't even know the names of our children, which was incredibly difficult for them.

- 29. When Tony was in St George's he had his own room because he was HIV positive. This happened right up until the end. The hospital said that he should be stimulated and that he should use the TV in his room. One day I went to visit and found the TV was gone. When I asked the nurse about it she said that Tony was not using it and so they had moved it to another patient. I was furious so I took in a small TV from home. I had to use Zoe's pushchair to take it into the hospital.
- 30.In 1993, when Deborah returned from Hong Kong, Tony collapsed with pneumonia and was admitted to St George's. By then he was wheelchair bound.
- 31.I recall him one day insisting that he wanted to go to Richmond Park. I was looking after Zoe who was only a baby and had to struggle her, the pushchair, Tony and his wheelchair into the car to go to the park. When we got there and I managed to get everyone out Tony walked to the edge of the car park using his zimmer frame and then decided he had had enough and wanted to go home.
- 32. That was the beginning of the end and I was regularly getting calls from the hospital where they thought that Tony might not make it through the day/night.
- 33. Tony came out of hospital for Christmas in 1993. Two days later he was back in St George's. I went to a meeting at the hospital with Dr Bevan and Tudor Williams (a social worker) and it was decided that it would be best to move Tony to a hospice.
- 34. We tried to have him put into St Raphael's Hospice (which was just up the road and therefore easy for me to visit). However the hospice refused to take Tony because he had HIV. I then made enquiries with the Mild May Hospital in East London who were brilliant. They even said that I could take the dogs in to visit Tony. Tony worried about the dogs when he was in hospital. They also would have had the facilities for him to paint. He loved painting. However Tony died before he could be admitted.

- 35. When Tony was ill I had no option than to keep going. We rallied together as a family and supported each other. I was fortunate that I also had amazing neighbours to help me out when things got difficult.
- 36. The stigma associated with the illness was dreadful, and we refrained from telling anyone about his disease unless they had to know because we knew that they would not come near us. We couldn't even get Tony a dentist to care for him.
- 37. The stigma of HIV and the way it affected us only got worse after Tony's death in 1994.
- 38. Tony was not able to lay in a chapel of rest and undertakers refused to touch him. The death registrar had told me they would only put pneumonia on his death certificate so we could avoid problems when it came to his burial; however this attempt was in vain.
- 39. We had made arrangements with our local funeral director, Frederick Payne, however when they discovered that he had suffered from HIV they refused to help. They called in another branch to deal with his body as he had to be buried in a sealed casket in a special segregated block. We were never able to see his body. I believe that someone at St George's told the funeral director about his diagnosis when they went to collect the body.
- 40. When Tony died his brother was on holiday and because no one was allowed to see the body he never got to say goodbye.
- 41. We were not offered any assistance and this was an incredibly difficult time for the family. At a time when we simply wanted to grieve, encountering so many problems in laying my husband to rest was very distressing and upsetting. We were not offered any counselling even though we had spent three days at the hospital and been to hell and back.
- 42. We have continued to feel that the true cause of Tony's death is something we have had to keep secret.

- 43. When Tony died his first grandchild, Zoe, was only a year old and our second grandchild was not yet born. This scandal has deprived me of my husband for 24 years, my children of their father and my grandchildren of any real time with their grandfather.
- 44. Since Tony passed away, I have done everything I can to keep myself busy.

  The Prudential changed my rounds so that I had to go to Croydon and in the end I decided to give it up.
- 45. I then started doing a lot of charity work which I continue to do to this day, and have helped to raise over £20,000 for local schools as well as numerous other causes. I also do paid voluntary work at a Sutton carers' centre.

### Section 6: Treatment/Care/Support

- 46. Neither Tony nor I were ever offered any form of counselling or psychological support at any stage of his illness or treatment or at the time of his death.
- 47. Tony's HIV infection was treated with AZT in 1991 as set out above.

## Section 7: Financial Assistance

- 48. We were contacted by the MacFarlane Trust and dealt with a social worker called Tudor Williams who was very helpful. He helped us obtaining funding for a stair lift to help Tony at home.
- 49. The Trust also arranged and paid for a carer to help me with Tony for a few hours each week when he started going downhill. At that time I was working for the Prudential collecting in monies in the morning and evening and Tony was in and out of hospital. When he was at home I could not leave him on his own while I went out to work so a carer come in to help. However, on one occasion the carer they sent arrived and said that she wasn't feeling well. I told her she couldn't come into the house because I was worried about Tony's

weak immune system. Shortly after that we started using a local voluntary care service instead called Cross Road.

50.I also received a lump sum payment from the Trust in 2017 of £10,000. I was advised to pay this into a separate account because it would not be taxed.

## Anonymity, disclosure and redaction

51.I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I do not wish to be called to give oral evidence.

#### **Statement of Truth**

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

