

Witness Name: A Carbery  
Statement No: WITN3250001  
Exhibits: 0  
Dated: May 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF ANN CARBERY

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I, Ann Carbery will say as follows:-

#### **Section 1. Introduction**

1. My name is Ann Carbery of GRO-C  
GRO-C My date of birth is GRO-C 1957. I have two children and two grandchildren.
2. I have prepared this statement as the widow of Russell Eric Carbery, born on GRO-C 1954, who passed away on GRO-C 1993 as a result of receiving contaminated blood products.
3. **This statement has been prepared without the benefit of access to Russell's full medical records.**

#### **Section 2. How Affected**

4. I met Russell on my 18<sup>th</sup> birthday party following which we went out together on a date and our relationship blossomed. I was a trainee nurse at the time and I knew that Russell suffered with Haemophilia A.

5. Russell was treated at Manchester Royal Infirmary Hospital (MRI). I do not recall the names of his consultants. One of his consultants was Dr Ferrera who was very caring and we were sad to learn that she had passed away

GRO-C

6. Russell was treated with Cryoprecipitate at the beginning and then he received Factor VIII blood products. I believe he received British blood products.
7. He received home treatment and we attended the hospital together in order to get the supplies and most of the time we stored them in our fridge at home.
8. We were told that Factor VIII was a better and faster acting treatment. He went from the condition ruling him to being able to live his life as he could take Factor VIII prophylactically. It meant that Russell could do things which he had not been able to do before.
9. I recall watching a Panorama programme on blood products being imported from America. We were not aware about HIV at that time.
10. In or around early 1980s close to the time when our son Stuart was born, we were all called into a meeting at MRI. The doctors and the Elstree blood company representative told us that HIV was detected in blood and that there was a small chance it could be passed through blood products. Their attitude was dismissive. They told us it was nothing to worry about as Russell and other haemophiliacs at MRI received British blood products.
11. They told us that patients would be asked to come in for a HIV test. They told us not to worry if the test was positive as it would not mean anything significant anyway. They were not worried so we didn't worry on that basis.
12. Russell was invited to be tested in approximately 1984. They said that if the result was positive, I would have to be tested as well. We went to get the results and they were unaware whether it was a "positive positive", or a

"positive negative". This was a very strange thing to understand and I was not sure what that meant. They were not sure whether he would develop AIDS.

13. I tested negative. We were told to be careful using needles when Russell was administering home treatment and to have safe sex to prevent transmission. There was no counselling offered and we were told to go home and get on with our lives.

14. He was provided with no information about treatment or prognosis. MRI never gave him any treatment for HIV. He received AZT treatment at Wilmslow Hospital, Manchester in the last 12 months of his life.

15. Russell was told in passing that he had Hepatitis B. At that time, it was common knowledge that nearly everybody had it and that it was the norm. He was told that he was positive and that it would not really affect him but that it would sometimes flare up and make him feel ill and then go back down again.

16. In the early 1990s we were away on holiday in France when Russell's skin turned yellow. We thought that the cause of the yellowing was Hepatitis B. Upon our return, MRI stated that it was not Hepatitis B and dismissed the condition. Russell's skin continued yellowing and suffered from night sweats which tied it to HIV. I went to see my GP and asked him whether he would refer Russell to Wilmslow Hospital as they were well known for HIV treatment. I took him away from MRI to Wilmslow Hospital as MRI was not providing any treatment or support. In January 1993, we attended a consultation in Wilmslow Hospital following which it was found that Russell had suffered with Hepatitis C. It was too late for Russell to begin treatment and he died in GRO-C 1993.

17. I recall Wilmslow Hospital referred Russell to have a gastroscopy, because he was suffering from swelling of his stomach. This was how they diagnosed he was in the late stages of liver failure. The doctors were as shocked as we were to think that we were not told earlier that Russell suffered from Hepatitis C. At this point, Russell was too far gone to undergo treatment.

18. It is unthinkable that MRI did not tell us that Russell was infected with Hepatitis C. We were under the impression that when Russell became ill, it was all HIV related. He must have been infected with Hepatitis C for years as by this time his liver was in the later stages of failure.

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

19. I am not aware of Russell being exposed to any other infections.

### **Section 4. Consent.**

20. Russell was aware that he was being tested for HIV.

21. I was aware of being tested for HIV.

22. Russell was not aware about being tested for Hepatitis C and he received no treatment for this.

23. Our children were not tested for HIV or Hepatitis C as far as I am aware GRO-C

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### **Section 5. Impact**

24. By the time Russell was diagnosed with HIV, it had started to appear on TV. We didn't tell anybody about his infection. In the 6 months after his diagnosis, Russell went into a very deep depression and attempted to commit suicide because he thought that we would be better off without him because of the stigma.

25. We lived in a small village and every one knew he had Haemophilia and they all assumed he had AIDS. As a result, we received a lot of hate mail in the form of letters calling Russel and me "AIDS scum" and drug addicts. People

would avoid us on the street and cross the road to avoid contact with us. A lot of our friends experienced vandalism. My parents did not want anything to do with us.

26. The only people who understood what we were going through were other people in similar positions. Even now, I don't have friends as such as I don't talk about it. People think we are friends but then something comes along and you realise you are not friends. I don't want to trust people anymore. It is hard.
27. We were told to go to local family planning for condoms. I had been sterilised so every time I went to collect them I was questioned as to whether I was a sex worker. MRI did give out free condoms but they were rationed. There was no joined up thinking between MRI or the Wilmslow Hospital.
28. Around the same time of the TV adverts about AIDS, the headmistress received complaints from other parents at the school that Paula attended in fear that Paula might be a risk to other children. The stigma was everywhere. All parents stopped speaking to me when I picked Paula up from school. I did not have any psychological help from anybody during this time.
29. We lived in a bungalow at the time but as a result of Russell being unable to remain insured due to his infection, we lost the bungalow and had to move in to a council house.
30. Russell's employer knew about the Haemophilia as Russell was having more severe bleeds. I believe the employer assumed that this was linked to the other infections and Russell lost his job as a Tax Inspector for Inland Revenue which was devastating both mentally and financially.
31. Russell was diagnosed with HIV in 1984 and moved hospitals in 1993. The intervening period was very hard. I tried not to let the children know that Russell was ill. We avoided discussions and kept it a secret as best as we could. We were trying to shield our children from the infections as a precaution because we did not want them to be bullied at school.

32. I used to be involved as secretary of the North West Haemophilia Group. We had been involved at the National level when Russell used to go to Conventions about new advances and treatments for HIV. Through this, I became friendly with one of the ladies who ran the North West Group who asked if I would be interested in coming along and helping them out. I enjoyed this and I got to know what was going on in the community. The other side of it was that I got involved with more people who were infected so all I seemed to be doing was going to other peoples' funerals. All our peers were dying around the age of 30 so it was really hard. I looked at my husband and questioned how long he might have left and I questioned whether the same would happen to me.

33. I was training as a nurse when we got married. I left nursing and went on to do clerical work. When I had my children I worked as a child minder as it was easier to organise my time around the children's school runs. During this time, if I had shared information about Russell's infection with anyone it would have prevented me from looking after children and effectively earning money. In the evenings, I used to work in a bar. When Russell lost his job and we lost the bungalow, we decided that I should go back to practising nursing. I started working night shifts at the local hospice which lasted approximately 6 years. The hospice staff was brilliant and a big support to me. Our roles reversed, Russell looked after the kids and I went back to work to earn our household income.

34. A friend of Russell's telephoned me one day to see whether I fancied coming in to help with clerical duties and office management at the Manor House Group. Shortly after, I was invited to become the secretary. We used to do campaigning and fundraising. I got the group to become a registered charity. I was dealing with people who were as poorly as Russell was and I could start to see them becoming very ill. As a result, I had to step away from this role to protect my own mental health.

35. I had difficulties arranging Russell's funeral. Russell wanted to die at home and he did not want to go into MRI as children were not allowed to come in for visits. At that time, I was working the nights at the hospice and we knew the

end was coming. A few funeral directors said they would not touch him. I came across one company who were really good and I could not have found anyone nicer to help organise his funeral.

36. Physically, Russell was asymptomatic in relation to HIV and did not have side effects from the AZT treatment. He was relatively well until he became ill with Hepatitis C which developed into liver failure. His health deteriorated the most in the last 6 months of his life. The last 2 months of his life were especially scary as his health deteriorated even further.

37. His mental health deteriorated in the period after he was diagnosed with HIV. Following this he was put on antidepressants which helped him and mentally he continued to be in quite a good place. I admire his strength to this day. He knew he did not have long to live but he always said Haemophilia limited his time with us. He managed to find peace inside of himself and he carried on living as long and as best as he could. He was a lot stronger mentally than I would have been. He took a positive approach as far as he could and we made some memories with the children as a family. We should all live for the day as you don't know what could happen.

38. It is hard for me now. We used to go abroad and I would not want to get on the plane as I did not like flying, but I did those things in order to support him as much as I could. When he passed away, our children were so young, I could not give in to it because the last thing they needed was a mother going off the rails.

39. My health has since gone down hill since Stuart and Paula have flown the nest when they turned 18 and 21. I suffer from diabetes, fibromyalgia, depression and anxiety. There is a study which states that fibromyalgia and diabetes are both associated with continuous stress. I find it really hard at the moment as the Inquiry brings to the surface a lot of memories which I have hidden away for many years. My GP said it is PTSD as we are now living those moments in our heads over and over again. The thing that worries me is what will happen after the Inquiry. The only thing that is keeping me going is the anger and wanting to get it out so that people understand what has really

gone on. I believe that once the truth is out, we can all move on. This is what I hope for from the Inquiry.

40. Stuart went through a bad phase at school and he stopped attending during the last 12 months. He hardly left his bedroom. I tried to get some help for him but there was none available at that time. He does not have many memories of his dad which is very hard.

41. Paula has really taken off with the campaigning and has found friendships with many people who are in the same position. They are both very protective and I know if I ring them they will come over.

42. Paula is currently living with me together with her husband and their little daughter. They are building a house as they have found that it is cheaper than to buy one. Two years later and they are still here. When she moves out I can see Stuart moving in!

43. Russell's late GRO-C was also a haemophiliac who also passed away as a result of receiving contaminated blood products. When Russell died it really broke GRO-C as they were close and attended Treloars together in the early 1970s.

44. I do not know whether Russell was given any blood products at Treloars. I think the only treatment at that time was rest. If it was a really bad bleed, he would get a blood transfusion.

45. The impact which Russell's infections had on our lives is that we were just left in limbo. I really don't think people understand the impact this has all had. I have kept it all inside. I could not talk about it to anybody else. My children grew up telling people that their father died of cancer instead and not telling the truth. Holding it all inside has been very difficult and I feel that it has to come out now.



46. I am tired of living and I am tired of fighting. I just don't want to be here. When my children are looking at me when I am in this state makes me think that they do not deserve this and that they deserve so much better.

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

47. I am currently on a waiting list to go back into counselling. I received counselling about 3 years ago. I have had counselling support on and off before that. I had my first counselling in or around 2000 when the kids flew the nest. They no longer needed me the way they needed me when they were children. All my grief came to a head. Since then, I have been alright for a bit. Then I drop back down. It is a never ending cycle. Every time my mental health deteriorates, I have to go to GP to sort it out myself. I am allowed 6 sessions at a time and then the consultant needs to decide what happens after. I do find it helpful. It would have been more helpful a long time ago.

48. My kids were not offered any counselling, even when Russell died.

#### **Section 7. Financial Assistance**

49. Financially, it has been difficult. I received no financial help at all bringing up my children following Russell's death. The impact on my children is that they have missed out on so much financially and emotionally. They missed out on having a dad and the security that a father would have provided.

50. I was told that Russell's medical records cannot be found. I requested a copy of the records a while ago when I was told that I could claim from the Skipton Fund. I found out about the Skipton Fund from somebody within the Haemophilia community. I used to help with the Manor House Group as a secretary and I went on a lot of campaigning with them so I think much of the information regarding the Skipton Fund came from there.

51. I received both Stage 1 and 2 payments from the Skipton Fund. The only reason I got them is because Russell's death certificate states that he died of

Hepatitis. I was told that I would not have been given this money unless the death certificate stated this as the cause of death. The death certificate noted the causes of death as: Bronchial pneumonia, chronic hepatitis and Haemophilia A.

52. Financially, after Russell passed away, I was receiving only a widow's mother's allowance. I had to go back to work at the hospice and they changed the hours for me and let me work between school hours to help me.

53. Even now it is still hard, despite receiving money from the payment scheme. I used to get £1,000 from the MacFarlane Trust, but this was reduced to £750. If I ever needed anything, I had to go to them cap in hand.

54. Russell was given £60,000 in the HIV litigation as he was a married man with children. If he had been able to get life insurance, we would have not lost the house and we would have had more financial security.

55. I have only just found out recently that Paula did not go to University because she thought that it would put further financial strain on me.

56. Whenever I wanted to ask for something from the MacFarlane Trust, there always seemed to be an excuse as to why I could not have it. I had to obtain quotations from three different providers which would then go before a committee to decide if I was allowed to have it. In the end, completely put off asking for help. I always felt it would be a "no".

57. I have not been on holiday since a year after Russell passed away.

58. It sounds quite brutal but Russell received money from the MacFarlane trust, so when he passed away and our income dropped drastically, life was very difficult to manage financially. It was a while until we received regular payments. We had to go find money for the winter fuel which was also difficult.

59. I was 36 when he died and I was looked upon as a person who could go out and get remarried again. The MacFarlane Trust told me that I was quite young and the money was there for those who were affected by the HIV and once the people infected died I was not their responsibility anymore. It was set up for the infected people and not their dependants. In their eyes, I was too young to be a widow as I was only 36 so I was not looked at as a widow.
60. When Russell received the ex-gratia payment, MRI must have known about the infection. He was told in a meeting with Panonne Rapier in Manchester that unfortunately we would not have a case worth pursuing and it would not be going to court as most of the people would die before we go to court. The Government was giving us this money so we were told that all of us had to sign. Russell signed the waiver on the basis that unless everybody signed it, nobody would receive the money. It was signed on the basis of emotional blackmail.

#### **Section 8. Other Issues**

61. The Government knew what they were doing. I would like to see people held accountable for what they did. If it happened today it would be a different kettle of fish altogether. I would gladly see GRO-D  
GRO-D
62. Russell passed away quite early on and people did not know what to do or what to say. There was no comfort. Dr Ferrera was lovely and caring so we were all devastated when she died GRO-A. She really cared for her patients. The other doctors did not know how to handle it but I cannot blame and do not blame the doctors. I blame the politicians who knew about it and covered it up. There was no joined up thinking. They did not know what to do or say. The only glimpse of satisfaction was that maybe people further down the line would be treated better as a result of what happened to us.
63. During my work campaigning I have seen a letter from a Health Secretary to the Head of the Blood Transfusion Service which said that all donations in the

UK were to be tested for all viruses. If the blood was infected it should be used to treat Haemophilia as it would be cheaper and the clean blood should be sold abroad. They did it knowing full well that it was infected. Unfortunately, I do not know what happened to this letter as I cannot find it.

64. My personal view is that the politicians did not expect haemophiliacs to live as long as they have. They did not expect the widows, children and parents to live on and they did not expect us to fight. The ripple effect of this tragedy is clearly underestimated. My two grandchildren do not know their grandad. It is a shame because Russell would have loved the thought of grandchildren. He never expected to get married or to have children so having grandchildren would have been a wonderful experience for him.

**Anonymity, disclosure and redaction**

65. I do not wish to retain my anonymity.

**Statement of Truth**

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

Signed.....

GRO-C

Dated.....

28/7/19