

Witness Name: Caroline Carberry

Statement No: WITN2451001

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

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF CAROLINE CARBERRY

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I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12<sup>th</sup> December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I Caroline Carberry make this statement true to the best of my knowledge and belief and will say as follows: -

#### **1. Introduction**

1. My full name is Caroline Ann Carberry and my date of birth and address is known to the inquiry.
2. I am 45 years of age. I am the wife of Brian Carberry. I am a Chartered Accountant. Brian and I have a 14-year-old son.

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

1. My husband suffers from Haemophilia A.

2. I understand that as a child and young man he had treatment as a result of haemophilia on a number of occasions. This would have been common to many sufferers of Haemophilia and required to prevent bleeds into his joints.
3. I understand that he was treated with Factor 8 in respect of that process in the 1970s and early 1980s. When he received treatment at the Royal Victorian Hospital that was the main Haemophiliac Centre in Northern Ireland.
4. It is my understanding that although he was probably infected at that time, it was not until the 1990s that he was advised by the consultant who dealt with him, Elizabeth Mayne, that he had Hep C.
5. I met Brian when I was 23 and he was 30. It was 1997.
6. At that time, Brian was divorced. He was not able to find work. He was living with his father. He was trying to find a job, but he struggled with the illness and fatigue and could not hold anything steady down. He was also suffering from a lot of joint pain.
7. My family knew his family. It was my mother who told me that he was a sufferer of Haemophilia. I do not think Brian had deliberately withheld this information. I genuinely believed that he thought most people already knew.
8. I don't recall knowing he had the infection of Hepatitis C until a few years after we had met. He had been for one of his regular hospital check-ups and when I asked how he got on he mentioned they checked his liver count. I asked him what he meant, and he told me about being infected with Hepatitis C and that it was a result of contaminated blood.
9. I do not recall Brian ever being given any information about his infection. As stated above he would attend the Hospital for regular check-ups and, in those early days, when he came back, he would be reassuring, telling me everything was fine. In those early years

of our relationship and marriage, we were able to cope and get on with life.

### **3. Other infections**

1. As far as I am aware the only infection Brian contracted was Hepatitis C. A number of years ago, he received a letter stating a blood donor had died from vCJD and that he might have received blood products from this donor. As there was no way to test if he had been infected and no treatment available, he decided that he did not want to take any further action.

### **4. Consent**

1. I do not believe Brian was given any information about the risks of receiving blood products in particular factor 8.

### **5. Impact**

1. When I first met Brian around 1997, his health was not brilliant, but he just about managed to get by and we were able to make something of a life together. I had a good job and was the main breadwinner. Brian was dependant on benefits, which he was not pleased about but we managed to make do.
2. Our son Peter was born in 2004. I was told there was no risk of him having Haemophilia, as I was not a carrier.
3. In almost a perverse way, Brian assumed he was fortunate only to have Hepatitis C and not HIV. The latter we understood to be something of a death sentence. We, rather naively, thought that Hepatitis C was not so dire. In those days, it was difficult to

research the condition, there was not great access computers never mind the internet. With no detailed information we lived in somewhat ignorance. If I had known more about Hepatitis C, it probably made me more tolerant to Brian's health deteriorating. It would have prepared me better for what was to come.

4. Our life was far from perfect; Brian was not in the finest of health but we managed and coped until around 2011 when he was struck down with TB. It is my belief that Hepatitis C undermined his immune system so contributed to this.
5. During 2011 Brian started losing weight and generally feeling unwell. He went to various doctors and hospital appointments, but it wasn't until his health seriously deteriorated and he was admitted to hospital in May 2012 that he was actually diagnosed with TB.
6. By this stage Brian was under 9 stone and the TB was not just in his lungs but had spread throughout his body. He was put on antibiotics (normally for 6-9 months but due to the severe case of TB Brian contracted he was put on medication for a year) and kept in isolation for numerous weeks. To this day it is not known how he acquired TB, but it was explained that active TB thrives in people with reduced immune systems.
7. Brian started to recover but was once again rushed to hospital as he had suffered a perforated bowel. Brian was required to have two emergency operations and due to his weakened immune system ended up having an ileostomy. The TB has also damaged his lungs therefore after each operation he ended up being ventilated and required to be treated in intensive care for a period.

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9. I was also tested and was initially found to have latent TB but due to the stress of Brian **GRO-C** **GRO-C** However instead of focusing on myself Brian had just been discharged from hospital. He was very weak and trying to come to terms with having a colostomy bag. Instead of being a strong independent man he suddenly required full time care for a number of weeks if not months. Brian could not come to terms with having the colostomy bag and often became depressed. Thankfully after a year the ileostomy was reversed.
10. At the time I was just grateful Brian was alive. We had all survived this infection and looking forward to the future, little did I know what was to follow!
11. In 2014, Brian became aware of a new treatment for Hepatitis C, a drug called Havrni. Unfortunately, in Northern Ireland there was a big waiting list for that. He had his MP raise the issue and eventually it was agreed it would be assessed for a course of treatment. However, during that assessment he was diagnosed with Non-Hodgkin's Lymphoma. Brian had to have RChop chemotherapy over a period of 6 months. It was explained to us that there is deemed to be a connection between Non-Hodgkin's Lymphoma and Hepatitis C.
12. Due to this connection after being told he had cleared the cancer he was advised to commence immediate treatment for the Hepatitis C. Once again, he was required to take severe medication and

although the Hepatitis C is currently undetectable his body has already been damaged. His immune system continued to be low and he was more susceptible to infections.

13. Due to an ongoing parathyroid problem Brian was referred for a CT scan. In February 2018 the scan revealed that the Non-Hodgkin's Lymphoma had returned.

14. These were difficult years as Brian was seriously ill. He was in and out of Hospital on treatments. It naturally got him very down, he would become depressed and angry.

15. I would be working in a busy job as an accountant during the day. I would get home and be very tired and having to deal with a depressed and sometimes angry Brian. Life at home was very fraught and tense. Due to being weak, confused and dealing with the effects of the various medications Brian was often unable to leave the house. Even trying to do small jobs such as the washing up left him shattered and frustrated. Unfortunately, with no other release I often the only one he could vent his anger at!

16. Also, during his cancer treatments, Brian was put on steroids for a number of days after each chemo treatment. This made him very temperamental and for two days after he finished the steroids you could not go near him. Once we knew the pattern, I would make sure myself and Peter would stay out of his way.

17. It made him very short with Peter who was just a young lad at the time. He would be just shouting at him for just doing something like walking up the stairs. Brian was a ticking bomb. We were all walking on eggshells around him.

18. We both knew this was not the Brian we knew and loved and just tried to keep him calm until he recovered, however, it was a very difficult time.

19. Brian was scared about the Non-Hodgkin's Lymphoma. He often became confused when being bombarded with all the information and appointments. I would have to take him to consultant's appointments. It was me, who had to ask them what was happening, what would happen next, what was the prognosis? Brian wanted just to shut all that out.

20. It was a terrible time for me. I had to take charge of Brian, deal with his temper, at the same time hold down a busy professional job and bring up a young lad.

21. Brian would go through cycles that he would battle his way through whatever course of treatment he was on. When he came out, he would then lapse into what I call "why me" mode. He would get depressed and angry that he was having to put up with so much. All this that been put on him through no fault of his own by the infected blood. Some days he would be fine then other days he would be screaming and shouting. I do not know how I coped.

22. In December 2017 we booked a family holiday in August 2018 with a large number of us going to Spain. However, because Brian was diagnosed with relapsed Non-Hodgkin's Lymphoma, we were advised to not pay any further money towards the trip. In the end we cancelled it but insisted our son Peter still went with my mum and dad.

23. Brian underwent a different chemotherapy called ESHAP. During four separate treatments he was required to receive the chemo 24 hours a day for five days. They also advise relapsed Non-Hodgkin Lymphoma patients to go through a stem cell transplant. Although

this will increase the chance of the cancer not returning it did involve being giving an extremely high dose of chemo and staying in an isolated room for approximately six weeks. Thankfully, at an appointment at the beginning of November he was told that the cancer was once again in remission. Although Brian remained poorly this was of course a huge relief.

24. Meanwhile he developed something of a cough. His health started to decline again.

25. On the 23<sup>rd</sup> November 2018, he was readmitted to Hospital with pneumonia.

26. He continued to decline rapidly and had to be moved to the Intensive Care Unit. He started to improve, was moved back to a regular ward but then suffered a collapsed lung. He went back to ICU and this time had to be ventilated and sedated. He was on a ventilator for 11 days. He was in hospital over the Christmas period.

27. The cancer had of course been a terrible thing, but I always felt it was managed by the Doctors in Hospital. You tended to be aware and be informed as to what was happening and what would happen next. In contrast, the pneumonia was a complete unknown. I was very frightened. I thought he was going to die. There seemed to be no way of controlling what was happening to Brian.

28. Again, the cancer had been terrible, but I had, to an extent, been able to plan life around it. I was able to work, albeit taking time off at times for appointments and when Brian was particularly poorly.

29. With the pneumonia, I had to give up work all together and take a month's sick leave. I was so worried and upset that I was not functioning in work. I could not concentrate.



30. I am very lucky to have an understanding, sympathetic employer. If it was not for that, I do not think I would be working now. I was allowed to take that time off and also given the flexibility afterwards to work from home when needed. It was then of course one of the busy times of the year for Accountants, the month of January. I had fallen very far behind so had to work long hours during that month.

31. Brian came home on 3<sup>rd</sup> January 2019. I believe he came home a couple of weeks too early. He was desperate to get out of Hospital. We had to set up a bed downstairs for him. That's still the way.

32. He was very weak. To get him upstairs for a shower was like a sort of mountain trek with one of us in front of him pulling him up and one of us behind him holding him up. It would take him an hour to get up the stairs, to get in the shower and get back.

33. He has very gradually improved since then. He is still on oxygen, he is still very weak. His legs and joints are very sore.

34. At the moment Brian is fighting through the treatment. If he gets through that he will then revert to his "why me" mode. It is a vicious circle that keeps reoccurring.

35. I try my best, but it is a terrible struggle to cope. I have been on antidepressants for a year. It is only a mild dosage to take the edge off things, but I got to the stage where I needed something by way of support. I felt like I was left to look after Brian at home as he recovers without any kind of any physical support, no counselling no nothing.

36. The years since 2011 have been a nightmare and, in the recent months, that nightmare got worse. I seem to see my life in two parts, my life before 2011 and life afterwards. I have to be strong for

Brian and our son, but it is a terrible struggle and I often feel isolated and on my own.

37. I need to somehow keep my job. There is no way Brian can work. We have a mortgage to pay and hopefully in a few years a son to put through college.

38. My employers have been fantastic and supportive, but I worry as to whether I can keep such a good working relationship with them. There is bound to become a point where my employer must lose patience.

39. Being the main breadwinner, I do not know how we would manage at all if I lost my job.

40. As Brian has no immune system, he is required to have all his vaccinations again. We are hoping this will occur soon. We can't keep him isolated therefore the more he is in contact with other people the higher risk he is of catching an infection.

41. Because he has been so ill in recent years, Brian cannot be as much a father as he would like to Peter. He cannot take him to football, he cannot play a part in parent activities at school. When he has been particularly ill, he has been very temperamental with Peter and will often get upset thinking he will not live to see Peter grow up.

42. Peter can't really remember a time when Brian was not in and out of hospital. The last time he was admitted he simply stated how long is he in hospital for this time? This is normal life for us not unfortunately extraordinary! However like myself when Brian was seriously ill over Christmas it really affected Peter, he lived with my parents for two weeks, his school grades fell and his mood was also

up and down. Not only was I worried about Brian I was also worried about my 14 year old sons mental health.

43. Brian has a daughter from a previous marriage. She is planning to get married in the summer. In a way, this has given Brian something of a goal to try and get better for and work towards.

44. Brian has an elderly father who is in his 80s. The burden of looking in on and looking out for his father has fallen on me. It is another thing I have to do because Brian is so poorly.

45. Although this statement is how my life has been effected consideration should also be given to our extended families who have also been effected by Brian's condition. They too worry about Brian, his poor mum and step father could only visit Brian once when he was in ICU as it unsettled them too much!

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

1. Counselling or support had never been made available.

## **7. Financial assistance**

1. Around the time of the Archer Inquiry, Brian made an application to the Skipton Fund and got a pay out of £20,000.
2. In 2012, it was shown there was a link between Hepatitis C and Non-Hodgkin's Lymphoma. Due to that link, he was entitled to a further payment and received a lump sum of £50,000 and a monthly payment of £1,200 per month, which has risen to £1,500 per month.
3. Because of the Hepatitis C, it has been very difficult to get various financial services such as life insurance. We had terrible problems

getting a mortgage. In 1999 we were renting and I wanted buy a house. Because of his Hepatitis C Brian couldn't get any life insurance or jointly purchase the house, therefore I had to effectively sign that he was a tenant and he had to sign away any rights to the house.

4. A few years later when we got the lump sum payment from the Skipton Fund we were able to put his name on the house but he still cannot get life insurance. We have another 10 years on our mortgage.
5. We also find it difficult and often it more expensive to get travel insurance for Brian. Due to his illness and various treatments over the past year we were advised not to travel anywhere foreign for approx. six months or until Brian receives his various vaccinations however, I can imagine it would have been impossible to obtain travel insurance for Brian.

## **8. Other Issues**

1. I love Brian but the last few years have been hell for us. Our life together has been forever blinded by the Hepatitis C and the serious illnesses that Brian has developed as a result.
2. I genuinely fear for how we are going to manage in the future. It's a worry and concern that never leaves me.

**Statement of Truth**

I believe the facts stated and this witness statement are true.

Signed

**GRO-C**

Dated... 25/2/19 .....