

Witness Name: Susan Gorman

Statement No: WITN2753001

Exhibits: WITN2753002

Dated: February 2019

## INFECTED BLOOD INQUIRY

---

### FIRST WRITTEN STATEMENT OF SUSAN GORMAN

---

I, Susan Gorman will say as follows:-

#### Section 1. Introduction

1. My name is Su Gorman, DOB [GRO-C]1954 and I am currently of no fixed address whilst I am waiting to arrange the final resting place of my husband.
2. My husband, Steve Dymond, died on 23.12.2018 after being infected with Hepatitis C through contaminated blood products.
3. Steve was able to meet with Collins Solicitors who created a first draft of his witness statement, however Steve passed away before being able to sign this statement. It is exhibited at **WITN27530002**. I was present at the meeting and confirm that the content is an accurate reflection of what Steve said.
4. This witness statement has been prepared without the benefit of access to my late husband's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

## Section 2. How Affected

5. Steve was diagnosed with mild haemophilia A when he was 12 years old. Despite this, he continued to live a normal life and play rugby.
6. Steve and I met in Fresher's Week of university through the Russian Department of the University of Exeter in 1974. Steve was incredibly bright and was doing very well academically; he was on course for a first which would have allowed him to obtain a research grant to pursue a university career in Russian Literature.
7. He was initially treated with cryoprecipitate, and I believe he first received Factor VIII in 1976 for a bruise on his leg at the Royal Devon Hospital. I remember this well as it was the day after we became a couple.
8. Following this treatment, Steve would often become confused and he suffered from fatigue. I noticed a change in his behaviour but it is only now, looking back, that I can link it to his Factor VIII treatment.
9. Steve and I married on the 25.10.1980 (the anniversary of the Bolshevik Revolution). Shortly before this, Steve underwent a tooth extraction for which he received Factor VIII. His wisdom teeth had never caused him any problems and he was never given a reason as to why they had to be removed. They suggested it after a visit to the Haemophilia Centre and that the Factor VIII would make it an easy procedure. This is the first time that he had been properly made aware of Factor VIII; it was sold to him as a 'wonder drug' and he was not told about any potential risks involved.
10. In 1984, Steve bruised his hand in the garden and I advised him that he should go to the local A&E at Lewisham Hospital. He only went there for advice as to whether we should seek treatment from the haemophilia centre the following day, but one of staff took a bottle of Factor VIII off the shelf and treated Steve without discussion. The next day we contacted UCLH who said that Steve should not have been treated with Factor VIII for a minor injury, as it

was only being kept in stock for the emergencies for severe haemophiliacs. They said that batch of Factor VIII had not been heat-treated.

11. Steve was tested for HIV which took 18 months, which was carried out at three monthly intervals. They finally confirmed that he was HIV negative in or about 1985. He was told that the incubation period for HIV could be up to ten years, which seriously affected his outlook on our personal life and our ability to have children.

12. Steve and I moved away to live in France, and it was not until 1994 that we learnt that Steve had been infected with Hepatitis C. We were told at the Necker Hospital in Paris that he had the 1B genotype. However, Steve was told next to nothing about the virus other than the fact it was benign and that he had nothing to worry about. He did not receive any information regarding its prognosis or routes of transmission.

13. We didn't hear anything else about the virus until I was removed from an IVF programme in 1997 as a result of Steve's infection. It was here that Steve was finally referred to a liver specialist, Professor Hillon, who told us that Steve's infection would result in cirrhosis and premature death. We had no idea about the severity of Steve's condition and we learnt this news just one day after being told we would never have children.

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

14. We were told that Steve may have been exposed to vCJD. A specialist autopsy has since confirmed that he was not infected vCJD.

### **Section 4. Consent**

15. Steve consented to be tested for HIV however we had no idea that Steve was being tested in the UK for Hepatitis C.

### **Section 5. Impact of the Infection**

16. Steve suffered from what we called 'third term syndrome'. He always did extremely well in the first and second term of his academic studies and during his working life as a teacher, but really struggled in the third. As such we couldn't have a summer holiday because we would have had a miserable time.
17. Not long after he was tested for HIV, Steve was mentally in a very bad way and that led to financial chaos as Steve thought he was dying and any debts would be covered by the life insurance; Steve wanted us to have the best life together whilst he was still here. All of our bills were behind, we were behind on the mortgage and the bank wouldn't give us any more money. One day Steve went to the bank as I needed money for petrol. An hour later, I received a call from him in tears. He had gone out and tried to kill himself because there was no more money but ran out of petrol before he was able to slam his car against a tree. My mum crossed London lent me money so I could go and pick him up. His father then came up from Bristol, cleared our debts and set us afloat financially again.
18. I knew at the time there was something wrong with his health but I couldn't get anyone to listen. People would just say that he was like his uncle Frank, who went bankrupt three times and committed suicide. Steve wasn't able to get any medical help. His GP would always put things down to tiredness or the fact he had started a demanding career.
19. In 1987 we moved to France for a year because the Head of Year at Steve's school knew he was struggling and thought that a year away to go and learn French would do him the world of good. We fell in love with France and ended up moving there permanently.
20. Steve's health and behaviour continued to deteriorate in France. He would always be tired and would suffer from brain fog. He would often be in a terrible mood and get angry for no reason.

21. After the diagnosis in 1994, it was another four years until we properly learnt what Steve's condition really meant and that the way he had been acting was attributable to his viral infection. It was absolutely devastating learning about Steve's infection, but in a way it was a relief because it gave us an explanation for his irrational behaviour, anger and inability to concentrate that he had suffered from for so many years. From then on, we learnt how to manage our relationship and when Steve was in a terrible mood, I would be annoyed at the infection rather than Steve. It was both of us fighting against the problem rather than each other. We called the Hepatitis C 'Mr Grumpy'; it was the guest who came to stay.

22. I was told in the space of 24 hours that I would never have children and that my husband would die prematurely. From then on we decided that we wouldn't have a house and we would just live in hotels; I didn't want to be left in a big empty house with no husband and no children.

23. I always think about the children that we never had. The only reason we got married was so that my family didn't call our children bastards. We had a vision of how we wanted to be as parents, how we would raise them and how our lives would progress. We were going to move to Devon, our children would visit whenever they could; it was all planned out – but we were robbed of that opportunity. It is especially difficult to cope with over Christmas time as I am bombarded with adverts showing happy families - children and grandchildren – and it is a constant reminder of what I will never have. My failure to have children is also one of the causes of the break down in relations with my mother, GRO-D

24. If I had known about Steve's infection I would have gone to an IVF clinic immediately. It is considered a right in France and it is free for everyone, so we could have done it straight away. We also wouldn't have walked out of secure careers. We would have planned for a secure financial future.

25. One day Steve turned to me and said 'do you know how much I love you?'. I think he realised that with everything that happened, it didn't always look like love, but that love was always present.

26. I lost the person that I married. They say that girls marry men like their father, but I intentionally married the complete opposite. When I married Steve he was a kind, cultured, intelligent, lovely-natured man, however as a result of his infection he turned into the man I hoped he wouldn't; he could be aggressive, short-tempered and horrible to be around. But I could also see that underneath the aggression, he was crying inside wondering how it had got to this. I remember looking at Steve one day as he slept and simply thinking, 'I don't know you anymore'.
27. Steve went through two courses of treatment in an attempt to clear the virus. In August 2002 he was treated with Interferon and Ribavirin which lasted for 48 weeks. The side effects were absolutely horrendous; he lost weight, he couldn't sleep and he had no appetite or energy. Steve was unable to work again after taking Interferon as he just became so exhausted.
28. In 2014-2015 he was monitored for a year for suspected liver cancer with three monthly MRIs.
29. In 2015 Steve was treated with Ribavirin and Harvoni. This course lasted for three months and resulted in far fewer side effects than the previous treatments, and he was told that it had cleared the virus. This treatment resulted in neuro-sensory hearing loss.
30. It was so tiring dealing with the never-ending cycle of Steve's bad health, which has all stemmed from his infection and continued until his death. Steve suffered from severe cirrhosis of the liver, portal hypertension and had a tumour removed from his liver in 2016. He was in and out of hospital for much of the last few years of his life.
31. Since Steve's death on 23.12.2018, he has been moved from pathologist to pathologist. There was no pathology lab in Kent that was a high enough grade to perform his post-mortem, so they attempted to transfer him to St Thomas'. However, St Thomas' ventilation system had stopped working, and they therefore were unable to take on new patients. At one stage, they suggested

that they wouldn't even perform a post-mortem so I could finally get the death certificate. This absolutely tore me apart; after so many years of living with his infections, I need to know the real cause of Steve's death. I am still waiting for the post-mortem results and as such I still haven't been able to bury my husband.

32. What really upsets me now are the projects we had but never achieved. Things like going on the highest railway in Europe and going on a dog sled ride. There was so much we wanted to do together that now we will never be able to. Towards the end I even think Steve was considering restarting his Russian Literature PhD. We would joke that as he had such terrible health in the middle of his life, we would be adventurous and action-packed in our old age. We never got to do this.

33. Steve and I had a financial assessment carried out where it was suggested that our financial has run into millions of pounds.

#### **Section 6. Treatment/care/support**

34. Steve and I were never been offered any real counselling despite everything we have been through. Steve saw a counsellor in France for a short while and there was a MacMillan nurse for him to talk to during his cancer monitoring, but there was no lasting support available to him and no support for his viral infection.

35. There was absolutely no joined-up care for Steve. In 2016, as a result of the irreversible cirrhosis resulting from his Hepatitis C infection he developed Portal Hypertension which manifested in him vomiting copious amounts of blood. The first incident occurred in March 2016 and despite there being a bed waiting for him at his specialist hospital King's College Hospital, London, he was left by the East Kent Ambulance service at A&E at Queen Elizabeth The Queen Mother Hospital (QEQM), Margate early in the afternoon where he received no treatment, no diagnosis and no Haemophilia Care and discharged himself just before midnight because of the refusal to transfer him to London.

36. Following further telephone discussions with the duty Haemophilia Registrar at St Thomas's we got my husband to their service in our car where he was admitted urgently and treated successfully. We received a totally unsatisfactory response to our complaint to the QEQM Hospital.
37. We did also try (unsuccessfully) to deal with the ambulance situation to avoid any patient with special needs being dumped at the nearest A&E and thus being denied appropriate care.
38. In June 2018 my husband had a second episode of Portal Hypertension. He was dumped into Margate Hospital despite having a bed available at Kings College Hospital July 2018 and was treated with a high dose of Clexane for a pulmonary embolism which I now believe was an incorrect diagnosis. He was discharged whilst still bleeding internally and then readmitted to Margate who decided after 24 hours there was nothing else they could do for him and he was finally blue-lighted in extremis to Kings who saved his life. When he received the letter which confirmed there had not been a blood clot he walked around with the letter in his hand for three days sobbing. He never recovered his health after that admission and I want the Inquest to consider the role of this treatment in Steve's death.

## **Section 7. Financial Assistance**

39. Steve received the Stage One and Stage Two payments from the Skipton Fund.
40. Within a week of Steve's death, I was told by EIBSS that they would be stopping his monthly payments as he was dead. They would not even wait until I had a death certificate. However, when I applied for the payments I am entitled to as a widow, I was told that I wouldn't be able to receive them until I had received the death certificate. This ridiculous double standard which was only resolved by the direct intervention of the Minister, three times, meant that I was really struggling financially. Fortunately, I was supported by the Tainted



Blood group who set up a GoFundMe page which raised almost £6,000. Without this support I don't know what I would have done.

41. The word 'support' in the title EIBSS does not seem quite appropriate given my experience.

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

42. I am annoyed by the constant changes to the name of the contaminated blood. Initially it was 'contaminated blood', which was later changed to 'infected blood'. I recently had a call from someone who said they were from 'IBI', which was pronounced as a word and not even the abbreviation! It is clear that they are constantly trying to water down the name in an attempt to not make themselves sound so bad.

43. For me, it is all about the information that was withheld from us. The infection of thousands of haemophiliacs is one thing, but the fact that we were lied to and not informed about these illnesses for so long meant that we were not able to be sensible and make the right life choices. If I had known Steve was incurably ill I would not have given up my career and neither would he. If I had known about his illness we could have planned for children earlier and we could have made better financial decisions and put more emphasis on planning for the future. But we were not given the opportunity to do any of these things and we didn't realise that our future was limited. Steve was far too young to die.

44. The Government is determined to make us look like the bad guys and money grabbers who want more and more, but that simply isn't the case. We want the truth and fair compensation.

45. The ethos of the Department of Health has been to dehumanise those infected and affected. They employ people to deal with the fallout of the scandal who either have the mind set that we aren't worthy or are so ill

informed that they shouldn't even be involved in dealing with the victims of this scandal; we are just a number to them.

46. I would like to see jail time for those responsible. I think doctors and others involved need to be named and held accountable and I would like to know why the drug companies involved have never been mentioned.

47. David Cameron promised us compensation in the PMQ's on 25.03.2015 on the anniversary of Steve's brother death, but this has never happened. All we have ever received is ex gratia payments in an attempt to keep us quiet. Steve and I are bright people and had promising careers ahead of us before his infection began to destroy our lives. If it had not been for his infection, we would be retired and financially comfortable. Instead, I am now widowed and hope that I have enough money to eat at the end of each month. Money aside, we deserve to be treated with dignity, respect and professionalism, which has been lacking for so long now.

### **Anonymity**

48. I do not wish to remain anonymous.

49. I want to give oral evidence to the Inquiry.

### **Statement of Truth**

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

Signed

**GRO-C**

Dated

26.03.2019.