

18 FEB 2019

Witness Name: **CONVER, Collette**

Statement No.: **WITN0503001**

Exhibits: **WITN0503002 –
WITN0503003**

Dated: 14 / 2 / 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF Collette CONVER

I provide this statement in response to a request made under Rule 9 of The Inquiry Rules, 2006 dated 18th. December 2018.

I, Collette Convery will say as follows: -

Section 1. Introduction

1. My name is Collette Convery, my date of birth and personal contact details are known to the Infected Blood Inquiry.
2. I am currently engaged as the Managing Director of a computer software company. I am married. I have no children. I have three living brothers and a sister, my mother resides with my husband and I. My father is deceased.
3. I make this statement concerning **Colin Edward HEFFERNAN**, my other brother, who was born on GRO-C 1966 and died on 6th April, 1991 aged just 24 years. In particular, I wish to speak of the nature of his illness, how it affected him and our family, treatment he received and the impact it had on his and our lives. Through this statement I wish to give my brother 'a voice' in these proceedings.

4. My brother had Haemophilia. Whilst being treated for the same, he was infected by use of contaminated blood products, through which he contracted both HIV and Hepatitis. He suffered liver damage and other medical issues as a direct result of his infection, and subsequently died of liver failure – a direct result of his having been infected. During his later years he also suffered arthritis.
5. In so far as the arthritis is concerned, I cannot be certain that Colin suffered arthritis as a direct result of his infections as I believe that haemophiliacs are prone to arthritis as a result of their frequently bleeding into joints.
6. In support of the above, I now produce as my **Exhibit WITN0503002**, a copy of his **Death Certificate** (reference IAC 225390).
7. Prior to our discovering that Colin had been infected, we lived as a family with our parents in the Midlands. My father was then an unemployed factory worker and my mother a cleaner. My two elder brothers and sister had left home by then, and I had just completed a degree course, and returned home. Our youngest brother was still in full time school education.
8. I believe that Colin had either just started a degree course (at the Preston Polytechnic), or was about to start, when he was first diagnosed – I cannot exactly recall.
9. My brother had severe haemophilia, Haemophilia A, and was at that time, reliant upon a blood product known as 'Factor VIII' to treat bleeds he regularly suffered. He would inject himself with Factor VIII several times each week and had then been using it for a number of years.
10. Prior to Factor VIII, Colin had used a product known as Cryoprecipitate, but I do not know when, or under what circumstances, he changed from one form of treatment to the other. However, I believe that he had been injected himself with Factor VIII from about eight years of age.

11. Cryoprecipitate was a frozen product which had to be thawed out before it could be administered. When my brother Colin was a young child, each bleed he suffered necessitated a visit to hospital for treatment. I recall us having to wait for hours whilst the cryoprecipitate was thawed out, sometimes whilst Colin screamed in pain.
12. I believe the introduction of Factor VIII was deemed an advancement, as it was readily available and could therefore be used at home, or otherwise outside of the hospital environment. Colin only started home treatment once Factor VIII became available.
13. My brother was a haemophilia patient of the Walsgrave Hospital in Coventry where he was under the care of a Dr. Strevens and a Sister GRO-D who was a Haemophilia Nurse. Occasionally he was treated at the Birmingham Children's Hospital, and in his earlier years at the Coventry and Warwickshire Hospital.

Section 2. How Affected / Infection Occurred

14. My parents, Colin and I were unaware of the nature of Factor VIII, or from where it may have been sourced. I have spoken to my mother about this and know that she is adamant that she never received any warnings as to any potential risks associated with using this product.
15. None of the family were aware that Colin had been infected until we heard a television news story which reported the fact that haemophiliacs had been being given contaminated blood products. As a result, we contacted the hospital (Walsgrave), to learn more, and Colin was given an appointment to undergo a blood test – the hospital hadn't called him in, it came about as a result of our concerns and our having called them.
16. Colin went in for the blood test, and I subsequently attended the hospital with him, when he returned for the results. I recall that despite the gravity of the situation, we were kept waiting in a corridor for several hours.

17. During our wait, I distinctly recall that a man and a woman, seemingly a couple, left the doctor's office, both of them crying.
18. Finally we were called in to see Dr. Strevens who asked us why we were there? Having told him that we had come to see if Colin had been infected with HIV, his response was, "*of course he has been infected, all haemophiliacs have been infected.*" We were then invited to leave.
19. We received no explanations, no advice or guidance, and nothing 'in writing.' Our invitation to leave was worded as, "...*was there anything else?*" We felt that we had been wasting the doctors time, as a result of our ignorance and a failure to grasp the situation placed before us. We were embarrassed by the manner in which we were dismissed, and left having been given no opportunity of discussing the infections my brother had, and their consequences for him, his life, his family and friends.
20. With the benefit of hindsight, thinking about the couple I'd seen leaving the consultation room 'in tears,' I thought that they had to have been in the same position as us, and had been given the same bad news. I began to wonder if there had been a consecutive chain of appointments through which patient after patient had been delivered devastating news, and that by the time we were called in, the doctor could simply have become 'fed up,' and was then incapable of being polite.
21. Colin raised this issue with Sister GRO-D during the course of his following appointment and the doctor's conduct was simply brushed off as being merely a brusque character trait.

22. Sometime later (I cannot recall the exact passage of time), Colin was invited back to the hospital (Walsgrave) to see Sister GRO-D. He attended and was told that he should use protection if having sex, to avoid him infecting anyone else. I am unaware of any other guidance or information he may then have been given, but do not believe that he received any.
23. Certainly, no advice had been given to any other family members, despite the fact that at that time various rumours were circulating as to how HIV could be spread. This included concerns that HIV could be spread through saliva, or from open wounds – a very significant risk in the case of a haemophiliac such as Colin.
24. I had assisted Colin with his injections, as had my mother, on the occasions when he had suffered bleeds in his arms and found himself unable to administer them to himself. I was worried that some time previously, I may have inadvertently pricked myself on one of his needles, but this situation didn't appear to even be being considered as a risk.
25. Colin received no counselling or other appropriate support of that nature at this time, despite his being just eighteen years old.
26. In the years that followed, prior to his death, Colin was advised that he had also been infected with Hepatitis, again as a direct result of his having been given contaminated blood product. I do not know when this happened, other than to say we were told of the diagnosis between 1985

and his death in 1991. I did not know of the type of hepatitis he had contracted or its severity.

27. Throughout this period, both Colin and I fully believed that his HIV infection would prove fatal in its own right, we didn't consider the hepatitis as an additional or further cause for concern and received no information as to that having been the case. We certainly didn't appreciate the impact it may have had upon his liver and liver function.

Section 3. Other Infections

28. Despite his age, Colin also suffered from arthritis, suffering pain in all of his joints.

Section 4. Consent

29. I do not believe that Colin was ever treated without his consent, but wish to point out that at that time, a lack of consultation and resultant inadequacy of information provided, was 'the norm' for hospital treatment and tests. It is perfectly possible that such a deception as this – the hospital not having declared the risks – could and did occur. Things went unnoticed.

30. As such, I do not think that Colin's consent could be regarded as having been 'informed consent.' There was categorically no mention made of any risks related to the use of these blood products.

31. It may be fair to say that we weren't a particularly educated family, but I would have thought that in such a case there would be even more of a necessity to discuss any associated risks with patients and those supporting them, in Colin's case, in particular regarding his age, his parents and immediate family.

32. Having said the above, there would not appear to have been any alternative means of treatment for Colin, at least, none were ever offered to him that I am aware of.

Section 5. Impact

33. When my brother first discovered that he had been infected with HIV, the media was full of stories about AIDS, tales of victims dying slowly and painfully. Colin believed that it was a foregone conclusion that he too would die that way.

34. He was studying in Preston and had the support of some good friends. He experienced little stigma associated with his condition but became too unwell to continue studying and had to return home.

35. At this time, I was working in the Midlands, installing a computer system for a major high street store chain. I was staying at the home of one of the store staff-members, not by choice, but as this was the standard practise for those implementing computer systems for these stores at that time. One evening, my mother and brother Colin visited me and my host made coffee and we talked.

36. During the course of conversation, Colin discussed his HIV status and there appeared to be no adverse reaction from the host. However, later in the evening, once I had retired to bed, for some reason I got up and returned to the kitchen where I found my host bleaching all of the cups we had been using earlier.

37. My host was looking very 'sheepish,' and commented to me that the cups "... *were due a bleaching.*" This was clearly untrue, but I didn't pass comment as I had no means of leaving, and no alternative accommodation available to me. However, I did appreciate that at that

time there was a lot of confusion as to how HIV may be passed from person-to-person and accepted it for what it was.

38. I didn't want my brother to experience the negative emotions I had experienced, the sense of indignation, and a feeling of how unfair it all was. He had a lot to cope with and was a very sensitive and caring person. He also had a strong sense of justice and would have been both very upset and aggrieved. As a consequence, I didn't tell my brother what had happened.
39. As Colin's health deteriorated, he began drinking heavily. He told me, when we discussed it, that he intended to hasten his death as he had no wish to die in the lingering way the media had portrayed.
40. Colin admitted to me that his greatest regret was that he had never made love to a woman and wouldn't be able to do so before he passed away. He told me that he was unable to take the risk of infecting a partner.
41. Colin enjoyed driving and would stop to draw landscapes – but after a wrongful conviction for careless driving, he became too nervous to drive for fear of losing his licence, and eventually stopped doing so.
42. As I have said (Para:20), Colin received absolutely no psychological counselling to help him cope with his medical situation, either when diagnosed with HIV or subsequently Hepatitis.
43. With hepatitis, his liver began to fail. His doctors insisted that he stop drinking, but he refused to do so, as a result of which they told him that they couldn't help him any longer. He was left to die, at home, with no medical assistance.
44. During his final months, Colin was unable to carry out even the most basic functions without assistance. He became senile and bedridden.
45. The only medical support he received was on the evening before he died. Two MacMillan nurses arrived. When they saw Colin, and his

condition at that point in time, they gave him a massive dose of morphine and he died early the following morning without regaining consciousness.

46. I would say that my parents were unhappily married. During this period their marriage totally broke down and they divorced in 1987.

47. During the break up of our parents' marriage, my mother, Colin and my youngest brother moved into my sister's home. Eventually my mother secured a small 2-bedroomed flat and was then living on benefits. I left my job implementing computer systems across the country and took employment in our home city so that I could be close to Colin.

48. Colin had a small box room and my youngest brother and I slept in the second bedroom. My mother slept in the living room. This was not as a result of our having feared infection, but because the small box room could only ever sleep one person at any one time.

49. On the day Colin died, my mother, GRO-C asked our GRO-C GRO-C to visit GRO-C Colin GRO-C GRO-C said that he was unable to come as he was 'waiting for a plumber to call to fix his boiler.'

GRO-C

50. Colin and I had always been very close, friends as well as brother and sister. I found myself then, and find myself now, unable to cope with the recollections of the painful and neglectful process of his death, and to this day am unable to reconcile myself to the trauma of the six years between confirmation of his infection and his death.

51. Following his death, I had suicidal thought for about three years, and still suffer bouts of depression, especially around anniversaries.

52. I was particularly close to Colin. I was the closest to him in terms of age and we spent a lot of our free time together, and I missed him desperately after he died.
53. My mother was absolutely devastated by his death. She had devoted her life to preserving his health, trying to minimise any risk of his suffering bleeds, and caring for him when he became incapacitated, but all in vain.
54. My father, by that time, was living separately to us, with little contact between him and the rest of our family. Colin didn't like his father, with good reason, but unconnected to the substance of this statement. Having been estranged from the family, he had been unaware of Colin's deterioration.
55. On the morning of Colin's death, my father was invited to the flat we were living in, to see him. Seeing his body he collapsed with shock. His death had a profound effect upon him, and often, whilst visiting my brother's grave, I saw evidence that he had been there himself.
56. When Colin died, our youngest brother was only about twelve years of age. I couldn't tell how he felt, but vividly recall his having collapsed at the funeral and having had to be carried from the church.
57. As a family, we had been quite reserved by nature, quite possibly repressed. My father had been a strict disciplinarian, someone who rarely spoke, and our home environment had been quite oppressive. We weren't people who spoke of our feelings, so I didn't have any insight as to how my siblings coped following Colin's death.
58. Following his death, none of us were ever offered, or received any form of counselling.

Section 6. Treatment/Care/Support

59. Colin did not experience any difficulty obtaining treatment, care or support as a consequence of his being infected with HIV and / or Hepatitis.

Section 7. Financial Assistance

60. Colin received a payment from a trust of fund in 1990, the year before his death. I do not recall who this came from, but I have possession of his bank books which reveal two deposits having been made, totalling £20,000- both on 1st February, 1990. The only organisation which my family and I were aware of, providing support, was the Haemophiliac Society, so I have always assumed that these payments were something which they had advised upon.

Section 8. Other Issues

61. Colin was infected with HIV as a direct result of his treatment by the Walsgrave Hospital. After being told that he had been infected, he nevertheless continued to treat his haemophilia condition with Factor VIII, in the belief that the blood product he was then being given, was, and would be, safe to use.

62. Whilst studying in Preston, following his HIV diagnosis, he was hospitalised with a bad bleed. The doctors there, in treating him, asked about the product he was then using to treat his haemophilia. When he told them what product he was using, he was advised to stop using it, because it was 'giving him AIDS.'

63. In light of the above, it appears to me, that Walsgrave Hospital had continued using contaminated blood products, even though they knew there was a risk of infection and it was public knowledge that people were being infected with HIV through tainted blood use.

64. To assist the inquiry, I now produce as an exhibit, a copy of the death certificate for my brother Colin Edward HEFFERNAN, GRO-C1966 – 6.4.1991 showing the cause of death and underlying medical conditions as: Liver failure, Hepatitis, Haemophilia and HIV [Exhibit: WITN05030002].

65. I also produce as an exhibit, a copy of articles I found whilst conducting my own independent research. This includes an item published by the UK Haemophilia Centre Doctor's Organisation (UKHDCO) entitled, ***'The Impact Of HIV On Mortality Rates In The Complete UK Haemophilia Population' (2004)***; an article on clinical trials and observations entitled, ***'Mortality Rates, Life Expectancy, And Causes Of Death In People With Haemophilia A or B In The United Kingdom Who Were Not Infected With HIV' (2007)***; an extract from Nature magazine (Vol. 377) entitled, ***'More Conviction On HIV And AIDS,' (1995)***, including letters submitted to this journal on the topic; and a further UKHDCO publication entitled ***'The Impact Of HIV ON Mortality Rates In The Complete UK Haemophilia Population' (2004)*** [Exhibit: WITN05030003].

66. I believe the information contained within these documents would be of benefit to The Infected Blood Inquiry showing medical knowledge and understanding as existed at various times across a broad period. Colin's consultant, Dr Streven's, contributed to this article.

Statement of Truth

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

Signed:

GRO-C

Dated: 14/2/2019