

Witness Name: Bernadine Lydia Rushton

Statement No.: WITN0134001

Exhibits: Nil

Dated: 12th June 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BERNADINE LYDIA RUSHTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23rd April 2019.

I, Bernadine Lydia Rushton, will say as follows: -

Section 1. Introduction

1. My name is name is Bernadine Lydia Rushton. My date of birth is GRO-C GRO-C 1962 and my address is known to the Inquiry. I am divorced and I have one son, who I shall not name as I would like to respect his privacy. I have been infected and affected because my first husband was given contaminated blood products. I intend to speak about my HIV and Hepatitis C (HCV). In particular, the nature of my illness, how the illness has affected me, the treatment received and the impact it had on mine and my family's life. I should point out that I have suffered from many different conditions over the years and still do. I have no written records and so I am going on memory, which is not very detailed. I will do my best to recall those things that are relevant to the Inquiry.

Section 2. How Infected

2. In 1984, I moved from my hometown in [GRO-C], Kent to [GRO-C] to study. I attended [GRO-C] College in [GRO-C] (no longer in existence), which was a college for disabled adults. I attended there, because I had severe arthritis in my knees.
3. This was where I met my first husband, Kevin John Hawkins. Kevin was slightly older than me, I was 22 years old, he was around 26 years old and was studying to be an electrician. I had been at the college for about six months when we started dating.
4. Kevin informed me that he was a haemophiliac very soon into our relationship. He had suffered from this condition all of his life. I am unsure of the actual categories of haemophilia but I believe his was severe.
5. Initially, I knew very little about haemophilia, other than it meant his blood had difficulty clotting. However, I came to know a lot more as we moved on together. Most people just think it means that if you cut your finger it doesn't stop bleeding, which is obviously true but it is much more complicated than that, including internal bleeds, such as in Kevin's case, in his knee joints which are very problematic and is the reason why Kevin attended that particular college. He had pins in his legs due to his condition.
6. Kevin regularly took a blood product named Factor VIII and he would self-administer this product around 3 or 4 times a week. He would generally administer it himself, or I would help. Later, his sister who was training to be a nurse did it too.
7. In 1985, we became engaged and moved from [GRO-C] to [GRO-C], Derbyshire where he was originally from. We lived with his parents there for around 18 months.

8. I did not work during this time, and Kevin had a job for a small period of time, but the company eventually got fed up with the time he would have to take off due to his illnesses.
9. Shortly after we moved to GRO-C, Kevin had a routine appointment concerning his haemophilia with Dr Maine at the Derbyshire Royal Infirmary. I attended this appointment with him and together we told Dr Maine that we were getting married. Dr Maine turned around to me and said "you better get tested for HIV then". I didn't understand why, Kevin had never told me that he was HIV+. I was absolutely shocked, this was the first time that I knew of Kevin's HIV diagnosis. I learned that he had been infected with HIV through the Factor VIII that he had been given to self-administer. I do not know when he first became infected or was diagnosed.
10. I had the HIV test, it took around 6 weeks for the test to return and it came back positive. I could not believe that Kevin had infected me with HIV, that he knew he had HIV before he met me, and that he had withheld this information. I was distraught, mad and I lost my temper with him. I thought about leaving him after what he had done to me, but back then I thought no one else would want me now.
11. Kevin never used contraception which would have protected me from contracting HIV. He was aware of his diagnosis, but I do not know what he was told by doctors in regard to infecting others. He would not wear a condom.
12. When I was diagnosed with HIV, I was pregnant. After I informed the doctor, he immediately told me that I had to have a termination. I was given no choice in the matter, I was 'forced' to have an abortion and I was 'forced' to be sterilised. I was told that I couldn't have children for fear of passing HIV to an unborn child. To say the very least, I was unhappy with

this but it went ahead, I felt I had little choice in the matter. Kevin wasn't happy about it either.

13. We then moved out of his parents' house to a council property for about four years.

14. In October 1990, we became aware of the MacFarlane Trust and together received payments totalling around £57,000. We used this payment towards purchasing our own property, the one I still live in. I believe this sum was made up of my payment of £22,000 for me and Kevin's payment of £35,000. I do not know the reason for the difference.

15. Following the termination of my pregnancy, I was depressed for years; I did not want anything to do with anybody. I was so desperate to have a baby of my own and this feeling just increased as time went by.

16. Four years after the termination, I visited my GP named Dr Mall, he was a very good doctor. I explained I really wanted to have a baby and that I wanted the sterilisation to be 'reversed'. I had been 'clipped', so it was possible to have it 'reversed', but because of my HIV infection no doctor in Derbyshire would perform the procedure.

17. The only doctor that would assist me was Professor Beard at St Mary's Hospital in London. The procedure was performed, he gave me six months to get pregnant (though I am not sure what would have happened if I wasn't) and it was 6 months to the day that I found out I was pregnant.

18. In 1991, my son was born, we were very lucky he was healthy [GRO-C]
[GRO-C] after Kevin, my son's father had died -see para 21).

19. In the run up to Kevin's death, the family were in Mablethorpe for 10 days on holiday. He had been suffering from a nose bleed and was rushed into Lincoln hospital. He was suffering really badly and it was very difficult for

me to deal with. He was also drinking a lot which did not help, but this could have been his coping mechanism for all of his health issues.

20. Kevin died shortly after, in 1994. The cause of death stated on his death certificate (a copy of which I have) is - a) Gastro Intestinal Haemorrhage and b) liver failure. It is also noted underneath that he was a haemophiliac. My understanding is that they do not put HIV or AIDS as cause of death. I should point out that the letter 'I' appears next to the a) for Gastro Intestinal Haemorrhage. My memory and view is that Kevin died as a result of HIV. His system had lost the ability to cope with infection, his immunity had eventually broken down.

21. A couple of months after his death, I was at a routine appointment for my HIV, and the doctor mentioned Kevin's HCV. It was at that point, I was tested and diagnosed with HCV. I was never aware that Kevin had been diagnosed HCV, and it was yet another infection he had kept from me, which I then found I had.

22. I met my second ex-husband, David Rushton, around two years after Kevin's death. I believe we married in around 1998, I don't remember exactly. David had always been fully aware of my HIV and HCV, and he was fine with it. He would not take any precautions to prevent him being infected. We were married for seven years before divorcing. David is still alive, though I am not in contact with him. I am unaware if he contracted HIV or HCV.

Section 3. Other Infections

23. Aside from HIV and HCV am not aware of any other infections that either I or Kevin have had as a result of the contaminated Factor VII he had been supplied with.

Section 4. Consent

24. I do not believe I have been treated or tested without my knowledge, or consent. I do not know about Kevin in this regard.
25. However, I do believe that I was persuaded with some coercion, to have a pregnancy terminated and then to be sterilised in order to stop me passing on the HIV. Given that I did subsequently give birth to a healthy child, I can say though, that while most likely done with the best of intentions, that this was not justified.

Section 5. Impact

26. I do not look at myself as a victim and I will keep fighting; my family are fighters. However, I do sometimes get fed up of having HIV and wonder why it happened to me.
27. My family and friends are fully aware that I have HIV and HCV. My mum has been fabulous with her support. I have two brothers; my eldest brother believes that it is my fault that I have been infected GRO-D
GRO-D. I haven't seen this brother since Kevin died.
28. My family have been impacted by my HIV diagnosis. My mum is 85 years old, she is unwell but due to my general health and in particular my mobility problems, I am unable to see her as much as I would like to.
29. One evening I went into the local pub with my husband and a remark was made by another customer, he said loudly, presumably to the staff, but for all to hear "I hope you're throwing those glasses out". I used to carry paperwork with me which stated that others were not at risk etc, I

threw it at him and said "Read it!" and walked out. Since this event I have never had any other problems.

30. When my son was a child, I informed his school of my diagnosis and somehow this information got back to the children. On one occasion a child said to him "your mums a prostitute junkie" and this ended with him getting into a fight. However, this is the only occasion that I am aware of. My son rarely had incidents like this but normally but he would always stick up for his Mum.

31. As a child, my son GRO-C
GRO-C However, I'm not entirely sure to what extent my HIV and HCV (or his Dad's) has impacted him. He does not talk about it as he doesn't want to upset me, but I do know he struggles sometimes.

Section 6. Treatment/Care/Support

32. In the early days I found it difficult when attending the dentist, as they would wear layers upon layers of gloves and a huge mask, but I no longer experience this. Further to this, there was an initial reluctance by my doctor to treat me but this was quickly resolved. I used to have lovely teeth (and nails) but they are no longer as good as they used to be. This is symptomatic of having HIV.

33. After I was diagnosed with HIV, I would visit my doctor every three months, and we would discuss whether or not I needed treatment.

34. I didn't like my local doctor. I ended up travelling to London where I met Dr. Mike Youle, a HIV Consultant at the Royal Free Hospital. Together we discussed my condition and he agreed to take me on and see me on a regular basis.

35. During this time, I was feeling very unwell; I was getting colds all of the time, I had diarrhoea virtually every day and I was sick. I would be shopping and I would urgently need to run to the bathroom.

36. In around 1999, I visited Dr. Youle in London for an appointment. He took one look at me in the waiting room and straight away he hospitalised me. I was in for 10 days and I was finally given HIV medication., the first I had had. I was told to take five huge tablets a day and I was on three different types of medications; one could have been AZT. The medicine would give me the shakes. The doctor changed my medication regime about six times.
37. Eventually travelling to London was too much for me and so I moved back to Derbyshire Royal Infirmary.
38. I cannot say specifically what drugs I have taken for my HIV in the past, but for about a year I have been on 150mg of Rezolsta once a day, 10mg of Descovy once a day and 50 mg of Tivicay once a day. I'm also taking other medications for high cholesterol, eczema, depression, arthritis, my slipped disk and asthma/hay fever.
39. Currently, my HIV has an undetectable viral load. I do not understand what 'CD4' means but I am aware the higher the reading the better. Following my diagnosis, it was 4 and now it is over 700 and rising at each appointment I attend. I used to go to hospital every three months for check-ups and now I can go every six months.
40. The side effects of the HIV medication are that I have difficulty sleeping but I choose not to have sleeping pills too often, due to me taking an overdose of them in my late teens (as a result of things that happened to me as a child). When it gets too much I do ask for help.
41. The HIV medication also cause diarrhoea, which in turn makes me thirsty.
42. After diagnosis, the implications of HCV were never explained to me. Other than the fact that it could mean I would need a liver transplant in the future. The doctor mentioned there were treatments available but

would only be used when required. Biopsies were carried out on my liver every year and so I knew my liver was okay.

43. In 2006, I was offered a treatment to cure my HCV. I started a 6-month course of Interferon. I injected it into my belly and I took tablets (which I cannot remember the name of) once a day.

44. During the treatment for HCV, I could not eat properly; I could only eat crackers every day and I was always tired. I would attend check-ups for tests every 3 weeks, and then went back 6 months after the treatment had finished and I was eventually told I was clear of HCV, and that my liver was unharmed.

45. I had counselling relating to my depression around four years ago but I have never been offered counselling for my HIV or HCV. Although I do believe generally, that I have had quite good support from medical professionals.

Section 7. Financial Assistance

46. I was first made aware of the availability of financial assistance in 1990 when the Haemophilia Society informed Kevin and I about the MacFarlane Trust, and I have been receiving monthly payments since.

47. It was the MacFarlane Trust, who informed me about the Skipton Fund.

48. I have received a £20,000 one off payment from the Skipton Fund and £22,000 one off payment from the Macfarlane Trust (the payment I received along with Kevin when he got his). I have used these payments to help pay off my mortgage and to make adjustments to the house to assist me with my medical conditions.

49. I currently receive £2,600 per month from England Infected Blood Support Scheme (EIBSS).

50. I also receive a £550 winter fuel payment annually.
51. Other income comes from Universal Credit, which is £532 per month.
52. GRO-D left me in a lot of financial mess whereby I had to re-mortgage the house. So, at one point I received a £7,000 one off hardship payment from the MacFarlane Trust. I very nearly lost the house and so this money was very useful.
53. At the end of this month I will lose my Disability Living Allowance (DLA) payments. The system has changed and the benefit is being replaced by Personal Independence Payments (PIP). I was assessed as not needing this. To my mind, this is wrong. When they visited me to make the assessment, they caught me on 'good' day. I cannot use buses with my condition, so I have had to buy a new car with my own funds before the car that I lease with the DLA money is taken away. I have appealed against the decision not to grant me PIP.
54. On 27th March 2018, I applied for Special Category Mechanism (SCM) through EIBSS, and I received a response letter on 12 April 2018 whereby I was told my application had been unsuccessful, because the doctors said that my symptoms/issues were not down to my HIV status. I was told that my regular EIBSS payments would continue and that I had the right to appeal. They have stated that I can reapply if my circumstances change but that I would have to wait a further 6 months. I believe that my symptoms are down to my HIV, but I have accepted the fact I have been denied this financial help. I have not appealed.
55. I have never been given any help to complete forms related to claiming financial assistance for Skipton, MacFarlane & EIBSS.

Section 8. Other Issues

56. I have tried to turn my condition into something positive and at the moment I am on the board of a charity named National Long-term Survivors Group (NLTSG), which is a charity based in the UK providing

support to people living with HIV. We have a weekend away four times a year. It is really nice to be around people that are also infected, as they know how I feel, and know what I have gone through. We have such wonderful weekends away, and I will be going away this weekend with them.

57. I have never taken any legal action against the NHS. I have never sought legal representation.

58. I do not have copies of my (or Kevin's) medical records, neither have I tried to obtain them.

59. My first husband was infected because he had no choice but to take that contaminated Factor VIII. I was put in a position that I should never have been exposed to. Though Kevin should have told me, the issue should never have arisen.

60. In my eyes, someone needs to answer why this blood, given to patients was infected in the first place. My understanding is that the blood was not screened and that it was donated by people in America that were not in the best of health or social circumstances like drunks, drug addicts and prison inmates. How could this ever be right? Who made these decisions? How long was it allowed to continue when all this became known? There are people and institutions that were responsible for this scandal and they should be made to answer these questions.

Statement of Truth

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

Signed GRO-C

Dated 12/6/19