Witness Name: Elizabeth Marie Slater
Statement No: WITNW3688001
Exhibits: Nil
Dated: 23 September 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ELIZABETH MARIE SLATER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 November 2019.

I, Elizabeth, Marie Slater will say as follows: -

Section 1. Introduction

1. My name is Elizabeth Marie Slater. My date of birth is GRO-C 1966 and my address is GRO-C Surrey, GRO-C I intend to speak about my sister Catherine Louise Slater **(WITN1732)** her infection with HIV, HCV and Hepatitis B from contaminated blood. In particular, the nature of her illness, how the illness affected her and our family, the treatment received and the impact it had on her, my family and our lives together.

2. I confirm that I am not legally represented and that I am happy for the Inquiry to assist with my statement.

3. My immediate family comprises of my mum, Teresa **(WITN3645)** and my Dad, James **(WITN3644)** my sister and me.

4. My sister is married to Kelly Whitworth **(WITN3670)**

5. I don't have any children and neither does my sister. I am 13 months younger than my sister.

6. I was married for 9 years but divorced in 2003 and currently live alone. I am a biology teacher, Academic Manager and Head of Department at a further education college.

Section 2. How Affected

7. My mother, sister and I suffer from an inherited bleeding disorder called Von Willebrands Disease, Type 2A which is classified as severe. I thought we were categorised as moderate but my sister checked with her haematologist, and we are severe suffers due to the low levels of certain blood clotting factors.

8. As young children, my sister and I suffered from nosebleeds and bruising, which are the main symptoms of this disease during early childhood. There is a professional photograph of my sister and I as children, the photographer failed to find a pose where a bruise could not be seen. During teenage years, the onset of menstruation caused yet more issues with severe episodes of blood loss to the point where treatment with clotting factors was required.

9. Even today, for me, there is rarely a day where there is not a bruise somewhere on my body.

10. We have all been treated with whole blood transfusions and various forms of blood clotting products throughout our lives. Unfortunately my sister required more Factor VIII products to treat her severe nose bleeds than my mother and me.

11. In the early days we were under the care of doctors at Manchester Royal Infirmary, and Preston Royal Infirmary in Lancashire, which was our local hospital. We were later transferred when I was 10 years old to Blackburn Royal Infirmary under the care of Dr Newsome at the Haematology department.

12. Our bleeding disorders were also overseen by Dr GRO-D at Manchester Royal Infirmary throughout. Due to a relocation to the South East of England, my Haemophilia Centre is now St Georges Hospital, Tooting under the care of Dr Steve Austin.

13. We had regular check-ups but my sister always had more bleeding issues than I did, it was one of those things, as she would have more nosebleeds than me. My sister was admitted to hospital a lot and I was admitted quite a bit for nosebleeds, which they would pack.

14. When I was 8 years old my mum gave me half of a junior aspirin for a headache. Nobody had told mum that we weren't supposed to have aspirin. I started to have a nosebleed so dad took me to Preston Royal Infirmary where they packed my nose and sent me home. Mum was worried because she knew something was wrong and when she noticed that my stools were black, dad took me back to hospital. I was bleeding internally. By then I had lost a lot of blood and slipped into a coma. The priest was called and he decided to confirm me at the bedside as I was, apparently, close to death. I woke up with everybody around the hospital bed praying. My mum remembers the doctor giving me some form of early blood product but she is not sure what it was.

15. Despite the severity of this example of how my bleeding disorder affected me, my sister bore the brunt of having this disease because she was in and out of hospital with nosebleed after nosebleed which made her anaemic, pretty much all of the time.

16. When we were growing up I realised that I was the less severely affected and therefore less troublesome child. I remember feeling like I had to be the 'OK child' because I witnessed my parents suffering from the stresses and strains of seeing their daughters bleeding and having to make frequent hospital visits.

17. My Dad was self-employed and trying to run a business and during our early childhood, Mum couldn't drive. This meant that Mum had to go on the bus to visit us in hospital during the daytime or get Dad to take us to hospital if we were bleeding. This put a lot of pressure on my parents. So due to this and the frequency of my sister's bleeding episodes, my sister was taught to self-administer blood products from 1980 when she was 15 years old.

18. It was under the care of Dr D A Newsome at Blackburn Royal Infirmary that my sister was trained to self-administer. This was delivered in dry ice and we stored it in the freezer at home. All the local children would come to see the plumes of chilly smoke from the dry ice when mum put it in the sink and poured water on it. During this time, my sister only gave herself the treatment when she suffered a bleed. Dr Newsome was an amazing consultant and we always felt very well cared for.

19. I remember helping my sister prepare the Cryoprecipitate because she was trying to stem a nosebleed and get the treatment ready. This is the bit I find most upsetting when I look back now. I used to enjoy helping her, we all did and I would on occasion push the plunger of the syringe to help her get the clotting factors in. The haematologist changed her treatment to Factor VIII Type Y in 1992 and I occasionally helped her with this treatment too.

20. It was the Cryoprecipitate that was later discovered to be the treatment that gave her HIV. It was traced back to a dose given in 1982 when I was 16 and my sister was 17 years old. To think I could have helped my sister infect herself is almost too much to bear. It might have actually been me that pushed that particular dose into her veins; I struggle with this thought to this day and try to block it out of my mind.

21. They traced the batch back to the blood of a male donor who had died a few years later of AIDS.

22. In approximately June 1985, my Mum, Dad, sister and I were called for HTLVIII testing. At the follow up appointment in August 1985, my sister was told that her test results were inconclusive and that they needed to take a further sample. They took samples from us all and at the next appointment Dr GRO-D informed my sister that she was infected with HTLVIII. I was not present when she was told this news but I understand that it was not delivered with much compassion.

23. In the following years, it became apparent that my sister had also been infected with Hepatitis B and Non-A-Non-B Hepatitis, now known as Hepatitis C. We have also been informed of the risk of contracting vCJD from the earlier, unscreened blood product and my sister has been notified that batches of treatment she received came from patients who were known to have suffered from vCJD.

24. Dr Newsome was devastated when he found out that his patients had been given contaminated products. He has almost made it his life's work to trace back and find the source of his patients' infections. He also tried to check where my sister's HCV came from, but that search proved inconclusive.

25. My sister was also infected with Hepatitis B, she got all of the viruses really. We only found out about the Hepatitis C in 1992. As previously

mentioned she was 17 years old when she had the batch that gave her HIV. At the time we were totally unaware of HIV, never mind the symptoms which we now know are flu-like in the early stages. We never noticed anything untoward at that time. We were a relatively normal and happy family in many respects but I don't really feel like we are now, after the traumas we have been through!

26. I was given blood products on many occasions, it was mainly Cryoprecipitate, but did not receive anywhere near as much as my sister.

27. As previously mentioned in 1985 when my sister was twenty years old, she was called in for testing because of the amount of blood product she had been given. I remember that there was lots of scary stuff on television at the time, the adverts with tombstones, etc. It was scary stuff and we were obviously aware of this at the time when Catherine was tested. I would have been 18 or 19 at the time and in my first year at University.

28. They said her first result was inconclusive and called GRO-C back for testing at Manchester Royal Infirmary. Then a few weeks later we were given the results, GRO-C all negative apart from my sister's. GRO-C GRO-C tested for HTLVIII, which is what HIV was known as back then.

29. I remember that I was a student at Manchester University at the time of our results, but my Mum and Dad were with my sister. My sister had a bad experience because the doctor, Dr GRO-D was very 'matter of fact' when informing her of the final result.

30. According to my parents' recollection of the consultation, Dr GRO-D announced that my sister had tested positive for HTLVIII. Dad was relieved as he thought that this meant she didn't have HIV. The doctor wasn't very clear. My parents passed this news to me. I can't remember if they visited me to tell me, I genuinely can't remember, I must have blocked it out.

31. I remember after finding out being so devastated that I couldn't speak; I think I just clammed up. It was so scary seeing all the news reports about people who were known to have HIV being targeted, their houses being spray painted with hate slogans. I don't remember talking to anybody and I felt that I couldn't really talk to anybody. I was in a surreal kind of bubble of family life and university life and I couldn't tell anyone. I kept it to myself.

32. I don't remember it affecting my studies. I am the sort of person that is able to withdraw from chaotic situations and focus on the one thing that I know will keep me afloat so I immersed myself in my studies. On reflection, this was my coping strategy, which I still use to this day, now it's teaching but then it was study.

33. During the holidays family discussions took place, which I found extremely upsetting. They centred round what we as a family could do and if we should tell anybody but we didn't tell anybody for many years. We were really struggling to come to terms with things.

34. I have been asked how I felt about receiving more blood products. It was Hobson's choice really, if we were bleeding we needed the treatment to stay alive but if we had the treatment there was the risk of infection. We had the treatment. If I needed treatment I had to go to hospital to receive it as I was never taught to self-administer. I don't recall needing too much treatment during my 20's. I think I must have just been lucky then. I vaguely remember the odd discussion with my haematologist about the dilemma of having the treatment despite the risk of infection and me asking how safe the treatment was.

35. I don't remember ever feeling like I wouldn't want to receive treatment because the treatment would be necessary. I think screening started to

come in soon after my sister received her test results. There were more reassurances that screening was being done after a certain point.

36. Whilst I was still attending University I remember having family discussions. I distinctly remember my sister struggling to deal with this devastating situation and the rest of us struggling in our own slightly disconnected way. Mum wanted to talk about it, Dad and I definitely did not. When we did get together Catherine I think wanted to talk about it but didn't know where to start, Mum wanted to fix it and make it better, whilst Dad and I just tried to hide away from it, we couldn't face up to it at all.

37. Catherine was offered some counselling at some stage but I don't remember when. I recall her coming back from a counselling session and suggesting that we should all go for family counselling. My immediate response was 'no'. I simply could not have spoken to anyone about it, not even a close friend or family member. I sometimes wish I had said yes as I believe now that it may have made a positive difference to us all.

38. We had all been living with each other as a family, eating doing everything together as you would. Dr GRO-D did talk to my parents about risks when he gave my sister the diagnosis. He was told my parents to use separate crockery for my sister and to put hers in separately on the hottest wash. They refused. They said something like "'we've all been using the same crockery until now so why should we change this"

39. After my sister's diagnosis, when she was bleeding I remember being more aware of her blood and thinking that we would need to be less blasé about handling the bloody tissues. I know my sister was scared for us when handling her blood. I felt a bit guilty about having such thoughts, she was my sister and I loved her, she was the same person she had always been. I felt bad that I was even thinking about the virus in her blood. It felt wrong.

40. I remember her longevity being talked about, we were constantly vigilant, looking out for signs of AIDS. It was stressful and emotionally draining. The torture for her and for us was too much to bear, never knowing when it was going to happen.

41. As mentioned earlier my sister was told in a matter of fact way. We all carried on with our day to day life as normally as we could.

42. My sister has always been gregarious, chatty, lively and loves being the centre of attention. She went off the rails really for quite a number of years after her diagnosis. I think that being told she hadn't got long to live, she thought 'I am going to just go for it!' She was a bit reckless and didn't think she needed to worry about having a healthy diet and lifestyle.

43. I think that living life with the idea that 'I am going to die soon anyway so I might as well do whatever I feel like doing' meant that when she didn't die within a year or two like she was told she would, she had to figure out a way to change that mind-set and this transition took an awfully long period of time.

44. She was training to be a nurse when she was told of her diagnosis, so she had real trouble getting through her nursing. She was training at Queen's Park Hospital, Blackburn. This had its own issues, being a part of the NHS where she had a condition which was potentially risky when in contact with other people and she was very aware of that. I think this shaped the nursing direction she went in, as she had always wanted to nurse in A&E but went into psychiatric nursing as it was safer dealing with broken minds rather than broken bodies.

45. My sister's diagnosis badly affected her studies, she was only halfway through her nurse training when she found out. She didn't manage to pass her nursing exams in 1985 took another 3 years to complete these as I recall. During this time I was studying for my degree in Biology at Manchester University.

46. I relied on my sister a lot, she was always there for me. She was the outgoing, fun, brave one. I was the shy, quiet one who relied on her big sister to lead the way. She broke every rule going which meant that when I followed on from her, it was easier for me as she had already done all of the forbidden things that my parents didn't want us to do.

47. I know that her diagnosis has altered me as a person. I recognised that if I was to survive a life without my sister ahead of me, I would have to force myself to forge a life on my own. We were in this trap of 'waiting for her to die'. We were emotionally very close and still are. I always had my sister to follow behind, paving the way for me and I wasn't prepared for her to not be there one day. It was such a worry. She was my rock and my focus, she was all I could see ahead of me and I was having to prepare to lose her.

48. Her diagnosis contributed to my decision to stay at home in GRO-C for a couple of years after my PGCE teaching qualification but I soon realised that I needed to become more independent. I moved away from home to make a life for myself without relying on my sister to pave the way for me. This was not easy as I am naturally quite shy and apprehensive about putting myself into new social situations.

49. I started to look for teaching jobs in various parts of the world: Canada, Spain. As a matter of fact, I never really wanted to be a teacher. I only signed up for the Post Graduate Certificate in Education course (PGCE) in order to force myself to stand up in front of people and be able to speak. I never intended to enter the profession following the PGCE but they are quite persuasive once you go on that course and once the feelings of absolute terror subsided, I began to enjoy teaching.

50. I studied it at St Martin's College, which is affiliated with Lancaster University. One of the criteria of the college's success was to get all of their students into job placements after qualifying. Luckily, the school

where I completed my teaching practice offered me a job so I worked there for 2 years to gain some teaching experience.

51. Teaching requires a huge degree of commitment and being up there, in front of a class full of students means that you have to stay focused. I think that really helped me to survive through the tough times. After the 2 years teaching in a school, I left home in 1990 to teach in a college in the south of England, 5 years after Catherine was diagnosed.

Section 3. Other Infections

52. We had a scare in 1986 when my sister was twenty-one, she became ill with Hepatitis B. My sister thought that it was the start of AIDS. That was scary. I remember that she was jaundiced. She was really unwell for a good 12 months and she decided to stop drinking alcohol for many years to follow in order to protect her liver. She got Hepatitis B infection from the blood products. They didn't determine the source of the Hepatitis B (or C) but her doctor thought that it was likely to be the Cryoprecipitate. She was still being treated with Cryoprecipitate at that time.

53. Two years later she was struck down with *Pneumocystis carinii* pneumonia (PCP), a bacterium that frequently lives in people's lungs but when immunosuppressed, it can cause an infection. This nearly killed her. She was hospitalised and ARC – AIDS related complex was diagnosed.

54. Pneumonia was the first sign that she had a severely low immunity and this bacterium was able to multiply in her lungs to the point where she was suffering from the symptoms of pneumonia. She was twenty-four years old then. A year later she was put on AZT, the first drug to treat AIDS. It was not a nice chemical but she managed to tolerate it, not many people could. My sister is very good at following the regime of taking drug doses and I think that is due to her nursing training. She is also incredibly resilient and confronts situations head-on. This helped her to tolerate the drug

regime also. Despite her, 'What the hell, I'm going to live my life and not worry about the consequences to myself' attitude, she followed taking her medication 'to the letter' and that is probably why she is still alive today.

55. My sister might even be one of the longest surviving people with HIV or coming up to it. She has done amazingly well considering what she has had to go through and is still going through. I would say she would rather be seen as a survivor. She has been so brave to have to deal with these infections and take all of drugs that she's had to take throughout her life. These are nasty drugs with horrible side effects; lipodystrophy, liver damage, kidney damage, etc. GRO-C

GRO-C

GRO-C I now receive Wilate to treat any bleeding problems.

56. I recently had keyhole surgery on my knee and some minor surgical procedures for which I was treated with Wilate, a factor VIII replacement. I used to have Haemate P. These blood products are supposedly screened and deemed to be safer than earlier treatments.

57. My sister remembers the Doctor and nurses at some point discussing something they referred to as non A-non B Hepatitis (now known as HCV) and in 1992 she was told that she had contracted this viral infection. During Dr Newsome's investigations into the source of my sister's infections he noticed signs of raised ALT in blood tests taken in 1990. He latterly believed that this was one of the early signs of her HCV infection. He was looking at it retrospectively and commented on this in 1997. HCV is a small virus, which is difficult to isolate and find.

Section 4. Consent

58. As far as I am aware both my sister's and I consented to the treatments given.

Section 5. Impact

59. In 1992 my sister was 27 and I was 26 when she was told about the HCV infection and I remember feeling that it was just not fair. I thought that I should have that (HCV), she had one and that I should have had the other. I felt guilty and still do.

60. One of the insensitive doctors (identity not known) said to my sister, "You don't have to worry about the HIV as much as the HCV, as that will be the one that kills you." It was so insensitive. It makes me cross and so upset that people can be so callous and thoughtless. As a biology teacher during the early days of AIDS and people 'coming out', I remember having questions about HIV and AIDS in class but I never disclosed my sister's illness to my students. I have told my Principal that I was part of this Inquiry but he was not unduly concerned and was of the same opinion as me that people need to talk about this.

61. My sister went through Interferon treatment first and it made her really low.

62. During those middle years after my sister was diagnosed with *Pneumocystis carinii* pneumonia (PCP), I remember thinking, what is this, what is going to happen and feeling helpless and thinking why has this happened, why has she got that?

63. It all came to a head on Christmas Eve, 1989 when Catherine was hospitalised with PCP, she was extremely unwell and suffering from a persistent cough and a sky-high temperature. She was admitted to a sideward and because of the HIV they wouldn't allow her to be treated on the main ward. I remember going back to the room with Mum and Dad,

the nightlight was on as it was late at night. Catherine's eyes were sunken with dark circles beneath, she looked dead and we thought that she was dead. We were all looking at her intently to see if she was breathing just as she opened her eyes.

64. Catherine opened her eyes, looked at the three of us standing in the doorway with the glow of light from the corridor behind us and said "Jesus, Mary and Joseph, have you come to take me away?" She thought that she had died and Jesus, Mary and Joseph were coming down to take her up to heaven. We can see the funny side when we look back on this moment, my family has a knack for finding humour in the face of adversity. Humour always got us through the difficult times, maybe people think that this is weird but I think it is our coping strategy.

65. During my teaching career, I think that my biology lessons on HIV/AIDS have maybe been some of the more useful ones to my students due to my understanding and perspective on this disease. In one discussion some students suggested that all AIDS sufferers should be put on an island and left there in isolation. I remember saying to the students, "How would you feel if it was your Mum, your Dad, your brother or sister or someone close to you who was HIV positive, would you still suggest that?" I wasn't upset with them because they were young and probably a bit scared about this new disease and they may have just been repeating what they had heard at home. I believe that this suggestion was borne out of society's attitude towards gay men. At that time, AIDS was predominantly associated with gay people, some thought it gave them the right to think it was ok to treat people unsympathetically just because they didn't' agree with their lifestyle choice.

66. At this time my sister was also struggling with her sexuality. I remember her asking me a question when I think we were teenagers. She said "What would you say if I said I was a lesbian?" Jokingly I said, "I'll never talk to you again" because I didn't think she was being serious.

67. When my sister did come out as a lesbian, my initial thought was that she had chosen this path because it was 'safer', it would help her to avoid penetrative sex and all of the conversations she would have to have around safe sex. Plus, it would mean she didn't have to suffer the painful realisation of not ever being able to have children. Due to HIV, having children was not an option for her at the time. I think she went through some troubled times and she was in turmoil. She is happily married now to a woman, the lovely Kelly.

68. Looking back I felt like I had lost my sister, as she wasn't the person she used to be. She was going through a lot of trauma and it changed her, she was not the carefree happy person that she was before she found out all these things and I think I felt like I had lost her really.

69. Mum and Dad have given a statement to the Inquiry as well as my sister. Mum and Dad are retired now but mum was an Occupational Therapy Helper and Dad was an engineer who ran various successful businesses with a partner. From my perspective, what Mum and Dad did was to become overly protective of both of us. We felt very much like we were the only ones who could talk about this and we all felt isolated. I know my Dad was angry and I am sure my Mum was too, but it was more noticeable in my Dad. Mum was more of a 'talker' about her feelings.

70. GRO-D My sister was quite offended by that but I thought it was fair enough back then. My sister remembers more about that situation than me. I think that I have blocked out anything too painful.

71. My sister was quite upset with him. Her view was. "Do you love her or not?" She had doubt in her mind, there was a bit of tension between Mum and my sister and him. Maybe he didn't love me as perhaps he should, or maybe I didn't love him as much as I should.

72. I am not sure what he would have done if I had been positive though and that was my sister's point. I was tested for HCV and the tests came back negative GRO-D I probably was quite concerned at the time about having the test but it had been a much bigger deal for me to tell him about my sister having HIV when I first met him.

73. My marriage didn't work out, we got married in 1994 and were married for 9 years and we divorced in 2003.

74. Back then I didn't form relationships very readily, but I was more concerned about having a sexual relationship, contracting HIV and giving my parents something else to worry about. So, I was the one who towed the line, the absolutely 'normal', doing everything right daughter. This probably spilled over to not really thinking carefully about what I wanted in my future life.

75. I now think I married someone who seemed to love me, just to have a normal life. I did love him but I also think that I ought to get married and have children. Needless to say, my marriage fell apart because I wasn't doing it for me, I was doing it for him, for my parents and for what I thought I had to do. Before marriage, I don't remember having a strong inclination to want anything in particular in my life, but my sister's HIV infection changed my focus. I was always on the skirt tails of my sister. I thought my sister wouldn't be around, so I needed to get out into the big bad world and find a life of my own, get married and have 2.4 children.

76. I was happy at university. I was quite shy but I made friends. I didn't have a boyfriend but I was meeting people and enjoying myself. I was quite studious and my attitude was 'I am here so I am going to work hard.'

77. It was a life defining moment when I was told that my sister had contracted HIV. It was during university that we were told that my sister had 2 years to live.

78. During the last 2 years of university, I focused on getting my degree. I went on to do a PGCE and became a teacher. I met my ex-husband when I moved to GRO-C for a job. We married in 1994 and divorced in 2003. I would have liked to have children but I didn't, it didn't work out as my marriage fell apart. I thought getting married was the right thing to do, I remember feeling that I had a duty to fulfil because my sister couldn't have children and a normal life. I didn't realise this at the time but I think I was going through the motions for my family. I wonder how my life would have been in another parallel universe where my sister hadn't contracted HIV / HCV / HBV.

79. I suppose we were a normal family up until the diagnosis and although we were dealing with pre-existing medical problems with my sister and I, there wasn't this overwhelming fear of this death sentence hanging over us. This knowledge of what could and most likely would happen to my sister. We could fix the bleeding, but we couldn't fix the HIV. They are now saying at some point HIV will be just like a common cold, there will be treatments that work so well that we will think of it as an infection of no great significance to our health.

80. Catherine was going through all sorts of stuff. In 1991 she retired from nursing at the age of 26. At that time she was forced to reconfigure her purpose in life. Early on in her retirement she was suffering terribly with ill-health caused by the viruses and she needed lots recovery time and care. Mum and Dad have always been there for us both but Catherine needed it more. She was also finding her way with her sexuality and was joining various support groups and clubs involved with the Lesbian and Gay community as well as HIV groups.

81. In 1991, as a family we all went on a haemophilia weekend to talk about issues around the virus and bleeding. It was the weekend of Mother's Day - Happy Mother's day talking about HIV and haemophilia!

82. Catherine later went to university and studied for a degree in Womens' Studies, she just about managed to be well enough to get through that. Mum, Dad and I were so proud of her achievement. Throughout this time, Catherine continued to talk about her HIV status and was receiving counselling on a regular basis.

83. Around the time of my marriage break-up, I was teaching at the college I am at now. I have a good friend at college who helped me through my relationship breakdown. About one year after separating from my ex-husband, I met someone else. I think I was pretty vulnerable at the time. After a year of being with him I felt it was necessary to get a divorce from my husband, although I was fully separated from him I was still technically married to him. From my own perspective, getting divorced wasn't a priority but I felt that it was necessary to sustain this new relationship. My ex-husband went to work in America leaving me to sell the marital home. Another chapter seemed to be starting but after one more year, that relationship ended too.

84. Every relationship just went wrong after that. I am just not cut out for relationships or for living with somebody. I think my past has not helped. In the early stages of relationships I find it difficult to get emotionally close and trust in the other person, I have this fear and it is not very helpful but I believe this fear stems from everything surrounding what happened to my sister.

85. Forming relationships means that I have to depend on a special someone being there for me. I think I have abandonment issues. I seem to be attracted to the more controlling partners who want to possess me and never leave. Unfortunately, these are the wrong type of partner for me. The trauma of possible loss of my sister may have some bearing on my struggle with feeling abandoned.

86. In 2001, situations arose when my sister had the treatment to clear the HCV she became very depressed. Her partner was a rather aggressive female. This partner was selfish and irresponsible, not the right person to help my sister through this difficult treatment. They got into debt and her partner took no responsibility for it. They were tough times for my sister, she became more and more withdrawn and as a result we didn't communicate as much as we should have back then. It felt like I had lost her all over again.

87. **GRO-D**

88. We had to get the partner out of her life and their house. My Dad told her she had to go and I don't think it was very easy, I am not quite sure what happened there.

89. A positive shift in my sister's life happened when she met Kelly. For many years my sister thought that would die sooner rather than later and it was only about 10 years ago that she thought, "I am not going to die, I better do something constructive with the rest of my life." She seemed to meet new people, nicer people. She also started to accept that she wasn't ever going to be well enough to hold-down a job. It was a slow process. She wasn't expecting to be retired off so young, she felt like a 'sponger' claiming benefits, she had to come to terms with the fact she shouldn't feel guilty about being too unwell to work. Her ambition was always to be a nurse, she was very good at it and it is such a shame as by now she would have been high up in NHS, in one of the top jobs.

90. For 5 years we didn't tell anybody about my sister's diagnosis. My sister decided that she wanted to tell the extended family, our aunties and

uncles. We didn't need to tell our cousins because we assumed that their parents would.

91. We had to do it in 2 batches, as we are a large family. She was amazing, she wrote down everything she wanted to say and read it out loud, face to face in our front room, she was so brave. When she finished reading, she told me that she ripped up those notes. I think that was Catherine's way of taking ownership of her infection and off-loading those past events. Up until then, we had all shared her infection story, we all co-owned it. She took it away from us. This was the first emotional release for me in front of people other than my immediate family.

92. Those 5 years of keeping it to myself became habitual for me. Keeping it in is not necessarily a good thing. You are actually the first people who I don't know that I have really spoken to about this. I usually only tell people I know well.

93. I have always thought that if I had counselling that would be a weakness but being able to cry in front of strangers whilst giving my statement has been cathartic for me.

94. I think the young me would be more proactive about doing something about the injustice; I didn't get fully involved. In the early days I had sleepless nights worrying about my sister. I think that if I am looking at myself now and looking back at my younger self, I would have tried to understand more about what was happening to my sister. It was too hard to hear all of the bad stuff and too painful to consider what lay ahead, but now I would be braver.

95. If it was the other way around with the younger me looking at myself, I would say, what are you doing there? I would never have thought I would end up living away from my family, alone with a cat as life alone is not what I would chose.

96. With regards to general stigma, I was brought up in the catholic faith. I remember going to a Christmas Eve service with Mum, Dad and my sister soon after we found out that she was HIV positive.

97. The Priest's sermon was about HIV and the fact that God works in mysterious ways, essentially what he was saying was this was God's way of punishing people for taking the wrong path. I wish I could have said, "Do you not realise there are people in your congregation that may have HIV?" I don't know what my sister must have been thinking. I never went to another church service although I did get married in church but I wish I had been strong enough not to go back into a church ever again. I realise now that it was just one person saying what he believed to be true but it is not a very Christian way of looking at your fellow men. I know I am very anti-religion now because of that.

98. Catherine has experienced stigma and she has campaigned against it by attending interviews on the radio, the Jeremy Vine's show for example. I haven't personally experienced stigma.

Section 6. Treatment/Care/Support

99. I have not had any problems with anyone refusing to administer dental care but my sister has had issues with dentists.

100. I have never been offered any counselling, which I think is pretty poor. None of the medical professionals spoke with us individually to see how we were coping; they just told us and left us with it. I think what my sister had to endure was just dreadful. She was told at the age of 20 that she

had a year or 2 to live, to not have sex or kiss anyone and to write her will - no aftercare at all.

101. We had another terrible time when I lived in Essex and I was still married. Catherine came to stay with us for my husband's 30th birthday party. Catherine was suffering from liver damage due to HCV and had previously had gastrointestinal bleeds. When she arrived she looked dreadful so I took her to my GP. We recounted Catherine's prior medical history to the GP and told him of our concerns. He thought we were being neurotic and tried to send us home. I am unable to recall his name. He tried to fob us off, GRO-C

GRO-C

102. GRO-C

103. I was livid with the GP, he hadn't take her seriously. The thing was that if we had listened to him, I would have taken her back to my home and she would have died. My mum wrote to the GP to let him know what had happened to Catherine. Mum was clever and wrote to him via recorded delivery so that he had to acknowledge receipt of this letter. He opened it the same day and phoned her. When she asked him for reasons behind his decisions, he said that this was only the second time this had

happened to him. My Mum said if it's the second time this has happened then it is two times too many.

104. GRO-C

GRO-C My husband's 30th birthday party was in full swing and I was supposed to be there hosting it.

105. I had the dilemma of whether to inform my parents. They were on holiday and I knew they would come home if I told them, I didn't want to cut short another holiday. I did tell them and they came home.

106. GRO-C

107. My car was still at Chelmsford general hospital so I had to get myself from Whitechapel to Chelmsford, which was quite scary at that time of night. I had to travel by Tube and train and got home an hour and a half later where everyone was still partying. It was really surreal, my sister had nearly died and they were all partying.

108. GRO-C HCV causes liver damage which in turn causes the blood to flow more slowly through the liver. This then puts the blood pressure up in the hepatic portal vein which brings blood from the gut, the rise in blood pressure causes bleeding in the gut.

109. In 2004 Catherine got a letter about risk of exposure to vCJD. I remember getting a letter too but I don't think mine said I had received blood from donors who were known to have died of vCJD. Catherine has had certain batches of blood product from people who have been known to have had vCJD, so her risk is much higher than mine. I haven't had a letter tracing blood products for any other pathogens.

110. Catherine's letter was probably along the lines of, you definitely have had batches whereas mine was more you may have been exposed to it. So I have sort of ignored it, I haven't worried about it which is maybe a bit silly but what can you do, My understanding is that you can't diagnose vCJD until you are dead.

111. In 2017 Catherine received a second lot of treatment to clear the HCV, they made a typo error and put down the wrong genotype for her HCV infection. Based on this genotype, they planned to give her Ribaveron. However, her HCV Genotype is 3 and this needed to be treated with Epclusa.

112. This drug was not allowed to be taken out of the country but my sister and her wife had already booked a holiday to coincide with the end of the Ribaveron treatment. So she couldn't go on holiday because her treatment went on beyond the start of the holiday and Epclusa couldn't be taken out of the country.

113. **GRO-C**

114. I think there are some very good health professionals such as Dr Newsome and a lot of other people who cared for us amazingly but there have just been the odd one or 2 insensitive doctors where you question what possessed them to become a doctor when they have little or no compassion. The bad experiences stick with you.

115. For me I think where I am at, I am still independent and still kind of giving the impression to my Mum and Dad that I am ok and they don't need to worry about me, but that is not always the case. They even say it, "Oh we don't need to worry about Liz."

116. It has in the past made me feel a bit over-looked; they didn't mean to, it's just that Catherine needed a lot of their attention because she was and still is not well. I give them permission to ignore me in a way. I don't mean it in a nasty way. They want to help me and I refuse and it is my own fault. It was the only way I could shield my Mum and Dad from having someone else to worry about.

117. I probably won't ever ask for help, I am just not used to it. That is how the family operates, I know Mum and Dad operate on the basis that no news is good news. So I operate on the basis of no news. I do tell them what is happening in my life, but not always the things that they have to do anything about. I often will have already dealt with such things before I tell them.

Section 7. Financial Assistance

118. Financial assistance doesn't affect me as I am working. My sister received the ex-gratia payment for the HIV infection under John Major's government but due to her acceptance of this she was later refused the right to claim for the Hepatitis viruses in January 1997. She has received some help here and there from the Macfarlane trust but I am unsure of the details.

Section 8. Other Issues

119. An apology from the Government who made decisions about allowing contaminated blood and blood products to be given to people is well overdue. The happy, successful, care-free life my sister deserved to have was taken away by John Major's Government. I want her to have proper compensation, enough money so that she doesn't have to worry about the future. At the moment, she has to ask for things that she shouldn't have

to ask for, and that upsets me. She has not had the life she should have had.

120. I probably haven't either, but I don't feel I've had a financial loss, because I would have done something similar. I was never particularly interested in pursuing a career for monetary reasons.

121. The reason I wanted to make this statement was because I didn't speak out when I should have; when we were all keeping it quiet. I wasn't brave enough to tell anyone or fight for justice.

122. The Inquiry team have been brilliant, I have been psyching myself up for this for a while. I was probably acting oddly recently because I knew this would be emotional. Despite finding this process challenging, I would be willing to give evidence at a hearing.

123. Since giving my statement before the Covid-19 lockdown restrictions arose, and on reading it over again I have made some minor amendments from the electronically signed version dated 14 April 2020. Therefore, I submit this signed copy as my final written statement.

Statement of Truth

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

Signed: GRO-C

Dated: 23 | 9 | 2020