Witness Name: CATHERINE LOUISE SLATER
Statement No: WITN1732001
Exhibits: WITN1732002-9
Dated: JULY 2019

# INFECTED BLOOD INQUIRY

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# FIRST WRITTEN STATEMENT OF CATHERINE LOUISE SLATER

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I, CATHERINE LOUISE SLATER, will say as follows:-

## Section 1. Introduction

1. My name is Catherine Louise Slater. I was born on GRO-C 1965 and I live at GRO-C, Lancashire GRO-C with my wife, Kelly. Kelly is a crisis support worker for a local council and I have been unfit for work due to ill health since the age of 26. Both Kelly and I have extended families living locally including my parents. I have one sibling, a sister, Elizabeth. She lives in Surrey.

2. This witness statement has been prepared without the benefit of access to my full medical records. Some of the documents I have in my possession are exhibited to this Statement where relevant.

## Section 2. How infected

3. I have Von Willebrand's Disease, Type IIA, classified as severe due to low levels of Factor VIII (0.26) and Von Willebrand Factor (0.34). My mother and sister also have Von Willebrand's Disease.

4. The Manchester Haemophilia Centre at the Manchester Royal Infirmary (MRI) has been the Centre with overall responsibility for my care throughout my life. I am currently under the care of Professor Hay. Before Professor Hay, I was under the care of Dr Wensley.

5. My initial treatment from the age of 18 months was that of whole blood transfusions administered at Preston Royal Infirmary (PRI) under the care of Dr Hesling. In 1976/77 I transferred to Blackburn Royal Infirmary (BRI), a regional satellite Haemophilia Centre, following the appointment of Dr D A Newsome there as Consultant Haematologist. I then started receiving Cryoprecipitate and was trained to self-administer it at home at the age of 15 in 1980. Cryoprecipitate was replaced by Factor VIII (FVIII) 8Y from 1992.

6. I am co-infected with the Humanimmunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) through contaminated blood products. I refer to **Exhibit WITN1732002** being a letter from Dr Newsome sent to me on 17th January 1997 which confirms that I was infected with HIV by contaminated Cryoprecipitate, HBV from contaminated blood or blood products and that Cyroprecipitate is also extremely likely to be the source of my HCV infection.

7. No information or advice was provided to me, my parents or my sister before treatment about the risk of being exposed to infections from blood products. The treatment was considered to be the best thing since sliced bread. I had very heavy periods and bad nose bleeds and would, constantly be anaemic. Without treatment I was unable to do anything with my bleeds. I needed to get the treatment in to me as quickly as possible. My parents and my sister, Elizabeth, would often need to help me by administering the treatment to me whilst I tried to stem the blood flow with tissues.

HIV

8. In or around June 1985, I was tested for HIV. I was told it was 'only a precaution' because I had been treated with British products (as opposed to

American or French). I was then contacted by the MRI to return with my family members some 4 to 6 weeks later for the results. At that appointment, Ms Burn, the Haemophilia Laboratory Assistant, hurriedly said that my test results were inconclusive and that they needed to take a further sample. At the same time, my parents and sister were also asked to provide blood samples for testing.

9. I was informed by Dr Wensley at the follow up appointment (another anxious 4 to 6 weeks later) that I was HTLVIIII positive. Dr Wensley was 'matter of fact' about it to the extent that my father, without any prior understanding as to what HTLVII was, misunderstood and thought it meant that I was clear of HIV. My father said "Thank God it's not AIDS" but his relief was very short lived. I do not remember my sister being present (she may have been back at University) but we were told that I *was* HIV positive and that of our family unit of four, I was the one, the only one, to be infected. I felt numb.

10. In retrospect I believe it likely (as do my family) that the original 'inconclusive' test result was in fact a positive one. Why else would the hospital want to test my parents and sister?

11. My parents were asked to leave the room and Dr Wensley proceeded to tell me that I had approximately two years to live and that I needed to sort my affairs out. I was told not to have penetrative sex with anyone, not to kiss anyone, not to even consider having children and to write my last will and testament. I should then try to enjoy what was left of my life. I was just 20 years old.

12. Dr Wensley then brought my parents back in to the room and asked my mum if we had a dishwasher. He said all my pots and pans, glasses and utensils would need to be kept separate from everyone else's and should be put on the hottest wash possible. My mother refused saying to Dr Wensley that we had all eaten from the same pots and cutlery previously and they had not contracted the virus as a result. She said "I am not doing that" and it would

only make me "feel isolated" from the family. The way in which my parents and I were told of the diagnosis was brutal.

13. Conversely, Dr Newsome whom I continued to see at regular appointments, made it his life's work to help and try to see justice done. As part of his investigations (and referring again to **Exhibit WITN1732002**), he managed to track down the source of my infection being a specific unit of Croyprecipitate I was given on two occasions in 1982. The implicated donor in the transmission of HIV to me and other patients died from AIDS in 1989.

HBV

14. I was told I was HIV positive halfway through my nurse training and I questioned as to whether I would be around to finish it. I was in a state of shock that lasted for a very long time, years and years. I became ill with HBV in 1986, a year later and I thought my illness was the start of AIDS.

15. I was excessively tired whilst trying to get through my final nursing exams. I had terrible nosebleeds which did not respond to any intervention or treatment and ended up having an allergic reaction to the amount of Cryoprecipitate I received and I ended up with hives and going into anaphylaxic shock. I was heavily jaundiced, exhausted and itching all over. I failed one of the papers. It was only when Dr Newsome tested my liver function and admitted me into hospital that HBV was suspected. HBV was not initially considered as the MRI should have ensured that I was vaccinated against it. It took 12 months for me to recover from HBV. I refer to **Exhibit WITN1732003** being confirmation of liability by the health authority in relation to which I received a compensation of £6,500. In the latter 6 months I sat mock exams twice weekly at nursing school (at my request) to ensure that I passed the final nursing exams that I sat and failed the previous year through no fault of my own.

HCV

16. From around the late 1980s into the early 1990s, I can recall the medical team around me talking about 'Non A Non B Hepatitis', how through studies they were trying to pin down the virus but, due to it's small microscopic size, it couldn't be isolated and identified. I was told that I had Hepatitis C in or around 1992, following the introduction of a viable testing process. However (and referring once again to **Exhibit WITN1732002**) Dr Newsome has confirmed that my raised ALT started to appear in 1990, believed to be the earliest laboratory evidence of my having HCV.

## Section 3. Other Infections

17. I was notified that I am at risk of vCJD in 2004 having been treated with the implicated batches of blood products from donors with the prion that causes vCJD. There is no definitive test and it can lay dormant for up to 50 years.

## Section 4. Consent

18. I am not aware of being tested for infections without consent. I have been asked to take part in treatment trials. I believe that I have been used as a 'guinea pig' but I hope that any trial, treatment or test result has been used for the advancement of science and to ultimately save lives and prevent further infections. By way of example, AZT was the only treatment drug available for HIV for a long time and there was little to no information about it's long term effects. Prior knowledge of the known long term effects would not have put me off taking AZT and in any event it had a hand in keeping me alive until better treatments came along. The AZT treatment I had caused lipodystrophy and I now have body dysmorphia something I have had to live with and would correct if it were possible.

## Section 5. Impact of the Infection

19. To be told I had HIV was surreal. Everything had changed and yet my body felt no different to the day before I was told. As a family, we decided to keep it

to ourselves because of the public reaction and fearfulness surrounding HIV and AIDS at that time. The fear of AIDS was at fever pitch. Tragic stories abounded every week of people being thrown out of their jobs, losing their lives, losing their loved ones, being rejected and turned upon by friends and neighbours, having their homes daubed with "AIDS scum" and being burned out of their homes.

20. When I was at home, we were miserable all the time, especially when talking about my diagnosis. It didn't feel like the infection was just mine, my family took part ownership of it, sharing the pain and anguish with me but individually I felt like I could not make any decisions about my own state of health. We had to convene to make decisions such as 'who would be told' and 'who couldn't or shouldn't'. I wanted my family to come to terms with this diagnosis in their own time whilst struggling myself.

21. I became very depressed and unable to cope. I had wanted to become a Nurse from being a small child. It was the only thing I wanted to do but in retrospect I wonder how I ever managed to complete the course and then keep working. My student group were very aware of AIDS and (without them knowing) I was what they were terrified of. I worked with people making comments about patients like "He's got AIDS. I'd need danger money to enter that room". I was nursing people back to their own state of health but in every aspect of my life I felt like an imposter, unable to tell anyone what I was going through. I felt diseased and a danger to everyone. I was fearful to let anyone help me or get close to me in case I passed the virus on to them. I was also incidentally trying to come out as gay at the same time as trying to come to terms with my HIV diagnosis. When I did come out to my mum her first reaction was 'like we have not got enough to cope with'.

22. None of our wider family and/or my friends and colleagues knew that I had HIV. I did not know who to talk to or turn to. I remember telling a colleague that I had HIV whilst under the influence of a few vodkas. Through fear of being exposed and ostricised, I tried to take it back assuring her it wasn't true

and that I had 'merely and unduly become concerned about catching it'. She did not believe me but to her credit she didn't tell anyone.

23. My worry and distress in relation to my infected status and very limited life expectancy was such that I could no longer function properly. I remember leaving my car headlights on and killing the battery three nights in a row. I ended up moving out of the nurses' home to move back home with my parents as I could not cope with living alone. Unbeknownst to my parents this was following a suicide attempt which was unsuccessful. At the time I did not disclose this attempt to anybody and I kept it to myself for many years. I felt that it was yet another example of not getting anything in my life right. It was the most isolating, depressing, frightening and scary time I have ever experienced.

24. When I became ill the year after being told I was HIV positive and was then told that that my illness was HBV and not AIDS, I thought 'Thank God its that'. I was convinced that I had now developed AIDS and that I had made it happen myself in waiting for that ticking time bomb to go off. After contracting HBV I stopped drinking alcohol and didn't imbibe for many years because every time I tried I got a raging headache and it took days to recover. A lot of haemophiliacs turned to drink to numb the pain. I did not want to be in a world where you drown your sorrows and wait to die. I decided that if I had just a few months to live, I had to live.

25. In 1990 I went on to AZT. During that Christmas period of 1989 whilst nursing in Whittingham (I was half way through my RMN training), I was admitted to hospital with PCP pneumonia. It was Christmas Eve. I remember the start of the illness because a few days prior to becoming ill my father and I went to see Preston play and we got beat 2-0. I was coughing and coughing throughout the game and just couldn't stop. I was upset after because a lot of people had told me to stop coughing. In hospital I was put into a side ward and pretty much left to my own devices. Other than Dr Newsome and my family no one wanted to enter the room. In my delirious state I thought Jesus, Mary and Joseph had come to take me home. It was in fact my parents and

sister at my bedside. Nurses and colleagues would just shout hello as they walked past. I now had an AIDS defining illness and was categorised as having entered 'ARC' AIDS Related Complex. It was like being diagnosed as HIV positive all over again. No longer was there any doubt. I was on the way to dying from AIDS.

26. In the early part of the following year (1990) with the blessing of my parents and sister, I told our extended family members. They did not know what to expect and I think they thought I was going to announce that I was coming out as a lesbian. We told my father's family one night and then my mother's family a couple of nights later. I wrote a speech that I read out loud. They were aghast and hung on my every word. I gave the same speech to both families and then I tore it up.

27. Around that time I decided to leave home. I needed to get out and live my life because I was dying. The tension at home was causing family arguments. It was like living in a bubbling pressure pot with the lid ready to lift at any time.

28. Prior to my diagnosis, I knew I wanted to pursue a specialism in nursing. After diagnosis, I thought a specialism in psychiatric nursing to be the safest option. I had dreams of being a Medical Officer in a women's prison or secure unit. I was working on an acute psychiatric ward when I advanced into ARC stage and I went back to training far too quickly because I didn't want to miss my training. I was also rapidly becoming too ill to work. I told a senior nurse who in turn told a senior charge nurse about my infected status and I was suspended. The staff did not want to work alongside me.

29. There was a big meeting about me involving the hospital big wigs of the time and the staff from the unit and the HIV specialist. I listened to the concerns and various scenarios to include the spread of infection if I was bitten. The HIV specialist was the only one to say anything positive about the situation. He said "You're lucky she has told you. Other HIV positive patients, doctors, nurses might not have told you or may not know. You should have things in place to deal with it so everyone can be treated the same."

30. I refer to **Exhibit WITN1732004** being a letter from BRI dated 22nd February 1991 advising me that they had no alternative but to retire me on health grounds and I finally retired from work at the end of that year at the age of 26 having worked for 8 years. I wrote a Will and chose the songs I wanted to be played at my own funeral. I bought a campervan with my HBV compensation (**Exhibit WITN1732003**) and set out across Europe to enjoy what I believed to be my very last experience of travel.

31. After that, and having also been informed that I had HCV, I carried on never knowing what would happen to me next. My family have struggled to come to terms with my infections. They have the added burden of knowing that they could have administered the treatment to me when I was bleeding out. They feel responsible, particularly so my sister Elizabeth. **GRO-D** **GRO-D**

32. My ability to sustain a long term relationship was severely adversely affected. I had low self esteem and was grateful for any attention. Before meeting and forming a relationship with my wife, Kelly, in 2011, I made bad relationship choices and became a victim of domestic violence, psychological, physical and financial.

33. In 2001 I had HCV clearing treatment for the first time. It was a 6-month course of Interferon and Ribavirin. I was tired, depressed and lost a lot of my hair. It made me feel suicidal. I was in my worst relationship at the time and I probably shouldn't have accepted the treatment. My then partner, stopped working ostensively to look after me during the treatment but she was drunk and abusive much of the time and I ended up with approximately £30,000 in debt. I refer to **Exhibit WITN1732005** being a letter from my Social Worker sent to my GP on 2nd July 2003 evidencing my poor mental state at that time. The treatment was at first thought to be successful but the HCV then returned. I could not face the prospect of undergoing further treatment and its side

effects once more. The doctors also refused to treat me with the same combination. They advised me to wait until better treatments came along.

34. I have been treated with large quantities of pills with unknown outcomes, dosages and side effects. Lipodystrophy changed my body shape and gave me a buffalo hump and fat-free legs. I have/had renal impairment, gastrointestinal problems, nausea, incessant diarrhoea, oral and virginal thrush.

35. I have developed heart, liver and kidney disease. I have been diagnosed with HIV Associated Neurocognitive Disorder (HAND). I have a calendar that I use as a memory aid and I write everything on it that I need to remember. Kelly reminds me to update it and refer back to it. I also write lists but still find it very difficult. The information I am able to retain depends upon my mood, anxiety levels and my level of fatigue.

36. I had no further HCV clearing treatment until 2017. They thought my Genotype was 1 and were going to put me on Ribavirin again in 2017. Kelly booked a five star all inclusive holiday for us to take to celebrate the end of treatment and our wedding anniversary. We then found out that the hospital had got it wrong for all these years because of a typing error and my HCV viral type was Genotype 3. They then switched the treatment plan to that of Epclusa but not before telling me how expensive it was and how it should not be taken out of the country under any circumstances. I had to go on a course to learn about the treatment and it's likely effects. This postponed everything by a month, so we had to rearrange the holiday at a huge additional cost. I was told how much each Epclusa pill was worth and they would only provide a month's supply at a time. I was told that if I lost the medication it would not be replaced. There would be no further funding for it.

37. The discussions surrounding treatment always result in Hobson's Choice for me. There are pros and cons and no guarantees. The Epclusa treatment was another drug trial. There were no studies of co-infected females within my age range or at all. Whilst on the treatment I felt brilliant and full of

energy. I was told by the nurse that I was cured to and go and enjoy my life. Within 6 to 8 weeks I was lethargic and sleeping a lot, three or four hours in the afternoon as well as at night. I became low in mood to then depressed with aching muscles, swollen hands and feet and could not even stand the duvet on my feet. I have spoken to Dr Hay about the effects at clinic. His only comment was that HCV would have been more damaging to me in the long run but the outcome of this new drug has been debilitating to my health. I have now developed fibromyalgia which is extremely painful and physically problematic for me.

38. I have come a long way in learning how to live again and not just survive. I have a First Class Honours Degree in Women's Studies, trained to be a reflexologist, I play 8 ball pool for Lancashire and I am a qualified pool referee. I have never been well enough to return to work despite my very best efforts but I have done voluntary work, grass root activist work, work with LBGTQ and feminist and HIV groups. I affiliate more with the LBGTQ community than the haemophiliac community because unlike most haemophiliacs I am a woman and a lesbian and I have Von Willebrand's too. I am different to them in every way. I have tried to retain my sense of humour and can laugh about my forgetfulness when I am with Kelly, my friends and my family members but my HAND and fibromyalgia diagnosis are illnesses I have to live with and manage on a daily basis. I try not to look back because I can easily spiral into depression. Being a core participant and providing a witness statement to the Inquiry has churned everything up to the surface again but it is something I need to do.

39. I refer to **Exhibit WITN1732006** being sections from a poster of a photographic history of my life made by a friend, artist and fellow HIV sufferer and activist.

40. I could have had a career. I could have been a mother (but did not want to risk passing the infection on). The thought that I might inadvertently infect others is a scary prospect for me especially in regard to by bleeding disorder as I bleed out rather than into my joints. With regard to my sexuality my HIV

has always been first and foremost in my mind which has affected my intimate life. I always feel like I have been controlled by my HIV and when I was younger it made me very sad and angry. When do you tell someone? What if they don't stay? It might be fine at first for them but as time goes on, and I have seen this time and time again, they start to withdraw emotionally and you can feel it happening. I could feel it happening. So it took a lot of time for me to have confidence in myself and a long term partner. I always thought I would be rejected in the end. When I was first getting to know Kelly I had a heavy bleed and I shouted at her not to come near me. Kelly without a fuss just grabbed gloves and tissues and got to it. She then stayed up all night looking after me. Whilst in a poor state physically, I am in a far better place mentally thanks to Kelly and my life with her.

41. In times past regarding stigma, my dentist would transforms from a normal dentist to an astronaut when she saw me just to clean my teeth. She put cling film on everything to include light fittings and door handles. Someone living in the same street once said they did not want someone like me living in their road. A friend I had years ago recently ran into my mother and apologised for dropping me as a friend. She said "I'm really sorry I couldn't stay friends with Catherine but I couldn't bear to see her die". My mother said "She hasn't died yet!"

42. I worked as a nurse for 8 years and was retired at the age of 26 thinking I would soon die. The loss of my career as a specialist nurse has had a significant impact on me financially.

## Section 6. Treatment/care/support

43. I was offered counselling by the MRI many years ago. I went once but the only advice given was for me to "Put my trust in God" and I didn't go back. But following an awful relationship I had CBT through which I became aware I was living for now and storing up trouble for the future and if I was going to live any length of time in the future I was going to have to live with the

problem I created. I therefore changed my behavior and starting thinking about tomorrow.

## Section 7. Financial Assistance

44. I received an ex gratia payment of £20,000 in the late 1980s and then signed the HIV litigation waiver and received a payment of £23,500. A gun was held to our heads to sign the waiver and settle the litigation on behalf of all those infected. I challenged the payment as £23,500 was for a single adult and I was at that time living as a 'married person' with my then partner. I refer to **Exhibit WITN1732007** being a letter informing me that the Government had refused me the married payment rate of £32,000.

45. I also lost a medical compensation claim in January 1997 in respect of HCV. I was unable to bring the claim due to the terms of settlement of the HIV litigation settlement because we signed the waiver. I refer to **Exhibit WITN1732008** being a copy of the letter from my then solicitors confirming that I was unable to bring my intended claim.

46. Referring to paragraph 33 above, I ended up in debt when I went through gruelling Interferon treatment in 2001 and a terrible relationship. I was very ill and felt vulnerable. I turned to the MacFarlane Trust (MFT) and they offered me a loan when I couldn't pay the rent and maxed out three credit cards. They offered me a loan of £7,000 in 2002. I refer to **Exhibit WITN1732009** being a copy letter I sent to the MFT in 2008 detailing the circumstances in which I accepted the loan in 2002 and my position as at 2008. I am an independent person and I have very rarely asked anyone for help. I felt like I had to go cap in hand and beg to those meant to help me when I needed them the most. I repaid the full amount. I felt that they should have helped me more, but I think what they saw was an angry, frustrated person.

47. Every year the MFT sent out the same forms for us to complete detailing our income and outgoings. You are expected to jump through so many hoops.

48. In January 2018, the MFT wrote inviting applications for grants to use the residue of available funds before they were wound up. With Kelly's encouragement I reluctantly applied for a grant for a new driveway. The original driveway was made up with tiny little stones and when I got in and out of the car I would slip. It was also a health hazard used by the neighbourhood cats. I was terrified of asking for help because I felt like I had to beg to them for help all over again. I had to obtain two estimates. The MFT wanted to pay the landscapers directly which created problems because I had to explain my circumstances, that the money was coming from MFT and reassure them that they would be paid. It created confidentiality problems. I worry about other people in the same circumstances having to tell strangers their business. I also believed the MFT were more helpful to those in the London locality where they were based. People in that locality that know the protocol always seemed to get the help denied to those further afield. I always it was 'London centric'. The closer you were the more support you got because they could travel to see you.

## Section 8. Other Issues

49. There are no other issues.

## Anonymity, disclosure and redaction

50. I am not seeking anonymity and I understand this statement will be published and disclosed as part of the Inquiry. I wish 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 ..............................

Date....28/8/19..........................................