Witness Name: Conan McIlwrath
Statement No:WITN1383001
Exhibits:WITN1383002-005
Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CONAN MCILWRATH

I, Conan McIlwrath will say as follows:-

Section 1. Introduction

1. My name is Conan McIlwrath, my date of birth is GRO-C 1982. I live at [redacted] GRO-C Northern Ireland GRO-C with my 9 year old son from a previous relationship, who I have shared custody of with his mother. I work full time for Northern Ireland Water.

Section 2. How infected

2. I have severe Haemophilia A. Growing up I was very aware of this, as I knew I had to be very careful with bumps and bruises.

3. As a child, as treatment for my Haemophilia, I received cryoprecipitate at a Hospital in England, which I believe to be Stevenage Hospital and then I also received Factor VIII blood products in Northern Ireland.

4. When I received infected blood products, I was being treatment at the Royal Victoria Hospital for Sick Children, Belfast. I was treated by a Dr Dempsey, a Dr GRO-D and a Dr Kerns.

5. I must have received infected blood products between approximately 1982 and 1985, as my parents say they were told that I had contracted Hepatitis C in 1984/1985.

6. My parents have informed me that I received cryoprecipitate and Factor VIII in the 1980s. I understand that I had my first bleed when I was about 6 weeks old, which was when I started being treated with blood products.

7. Generally I received treatment around twice a week, but when I had a bleed I would attend hospital more regularly. For example, once when I had an ankle bleed I was treated daily at the Royal Victoria Hospital for 3 months.

8. My Mum has told me that in the early 1980's, that the treatment for haemophilia was changing due to links between haemophilia and HIV starting to be made . I understand that in around 1983/4 they were trying out heat treated products and when they didn't use these, they were trying to use Scottish products on children, which my parents say they were told were as "pure as possible".

9. My Mum believes that there may have been times during my first or second year of treatment when I didn't receive Scottish products and when I may have received other Factor VIII products.

10. As regards information being given to my parents about any risks of me being exposed to infection as a result of receiving blood products, my Mum recalls that she was told by Dr Dempsey that I would never be given American Factor VIII. She recalls that he said that I would only be given Scottish Factor VIII or heat treated Factor VIII so that I would receive the purest products possible.

11. My Mum tells me that she put her faith in the doctors regarding the treatment they recommended. She thought that I had to have the treatment they recommended or I would bleed.

12. As a result of being given infected blood products, I was infected with Hepatitis C.

13. My Mum does not recall exactly when her and my Dad were told that I had Hepatitis C, but she thinks it was when I was around 2 or 3 years old. She does not recall being given any information about what the infection meant for me. My Mum says she remembers being told that all haemophiliacs had Hepatitis C and that she should not be concerned about it, as I would live a long and happy life.

14. My Mum is a haemophiliac herself and was also been infected with Hepatitis C as a result of receiving infected blood products. She was told she had Hepatitis C in 1992, but believes she became infected as a result of treatment she received in April 1980.

15. When I was around 6/7 years old, my parents have told me that they were called in to the hospital to see Dr GRO-D who told them that she had great news and that I had "cleared the virus".

16. However, she said that when she relayed this to Dr Dempsey, he was furious and told her that nobody "clears the virus", it just hides.

Section 3. Other Infections

17. I am unaware of any other infections that I have contracted as a result of receiving infected blood products, but this is always in the back of my mind. I wonder what else is going to rear it's ugly head and I often wonder about vCJD.

18. In 2001, I received a letter stating that I was not exposed to any of the batches of plasma-derived clotting factors which were prepared from an individual donor who later developed vCJD.

19. In 2004, I received a further letter stating that as a public health measure, as I had received clotting factor concentrates between 1980 and 2001, I was not

to donate blood, organs or semen and to inform all healthcare professionals who treated me (doctors, nurses, dentists) about the possible need to use disposable instruments (when treating me). I exhibit at **WITN1383002** the documents which relate to correspondence in my medical records regarding vCJD.

Section 4. Consent

20. My mother recalls me being tested for HIV, for which I tested negative. She is not aware of other infections I was tested for. She tells me that they took blood from me every 6 months or so to test.

21. Although I would not like to think I have been treated or tested without my parents' knowledge or consent, I think it is highly possible that over the years this has been the case.

22. I was once asked to give blood for research. A Dr Anderson and another doctor, whose name I cannot recall, conducted an investigation and I do not ever recall being given the results of the research that was carried out.

23. In my early 20's, I was asked to give an awful lot of blood samples, which I was told they wanted to take because I had cleared the Hepatitis C virus and they wanted to test my blood to see how I had done so. I have always thought that this was suspicious and have questioned whether this was true.

24. I exhibit at **WITN1383003** an undated extract from my medical records which refers to me being checked for Parvovirus, Hepatitis A, Hepatitis B and C.

Section 5. Impact

25. As a result of my infection with Hepatitis C, I suffer from tiredness and I notice that I feel more lethargic than most people the same age as me. Some times I have good days, but I never know how I will be on any given day. This can be challenging, particularly as I have an energetic 9 year old son.

26. With regards to other illness/conditions, I suffer from rheumatoid arthritis and irritable bowel syndrome (IBS). I have undergone a considerable amount of investigations and treatment under the care of a gastroenterologist for my IBS. I believe that these conditions may be attributable to my Hepatitis C.

27. I have asked Dr Benson, my treating Consultant Haematologist and the Haemophilia Director for Northern Ireland, about a possible link between my IBS and the Hepatitis C infection and his best guess is that it "might" be linked to me having been infected with Hepatitis C.

28. I feel that being infected with Hepatitis C has caused me to become very paranoid and anxious about my health. At the back of my mind, whenever I'm unwell I question whether it is because of my Hepatitis C infection. I cannot help but be concerned.

29. Not knowing the extent of the infection and the potential long-lasting effects is very daunting. I exhibit at **WITN1383004** a letter from Dr **GRO-D** to Dr Dempsey dated 5th December 1995, which says that no-one is entirely certain of the future for patients such as me.

30. I did not understand that I had Hepatitis C until much later in life, when it was explained to me by my parents. At this point, I began to wonder what the long-lasting effects could be. Dr Gary Benson, my treating Consultant, is very informative and will answer any questions I have about Hepatitis C. However, he has told me very little about the potential long-lasting effects of my infection. I have had to undertake my own research into this.

31. I have never needed any treatment for Hepatitis C, as I "cleared" the infection naturally.

32. Although I have "cleared" Hepatitis C, I have had to inform any partners or prospective partners that I have had the virus. This has not resulted in any failed relationships, but it has been a difficult discussion to have.

33. As regards the impact of the infection on my personal life, it is difficult not having the same get up and go as people the same age as me. I definitely get more tired than friends of mine the same age. I do have good days, but I never know how I will be on any given day.

34. It is frustrating for my son when I don't have the energy to do things with him.

35. It is difficult dealing with these symptoms as well as my rheumatoid arthritis and IBS.

36. My parents suffered a great deal of stress because of my illnesses. There are so many blurred lines between having Haemophilia and having Hepatitis C, but I know that my mother feels that it was unfair for me to be given more health issues as a result of treatment given to me by people in a position of trust.

37. I have never really felt any direct stigma due to my Hepatitis C infection. However, it was always something that I was concerned about because I worried that people might link Haemophilia to HIV.

38. Before the 1980's, people had rarely heard of Haemophilia, but after that people knew about it due to its connection with HIV. The first question people ask if you tell them you are a Haemophiliac is "do you have HIV?". When I was younger, I heard stories about the questions people have been asked about this, and this made me concerned about the stigma.

Section 6. Treatment/Care/Support

39. I have not been offered any counselling or support in relation to my Hepatitis C infection.

Section 7. Financial Assistance

40. When I was around 18/19 years old, I received Skipton Stage 1 payment of £20,000.

41. Following this payment, I did not claim anything until my previous relationship broke down, which was a very hard time financially, as I had to split most of the assets I shared with my former partner and start from scratch.

42. I therefore applied for financial support from Caxton. I felt like I was begging for help, but I had no problems with them and only had to fill out a form in order to receive a grant. I received about £1,500 to get myself set up with household items, which was a big help at a difficult time for me.

43. After my father was ill a few years ago, I was also given some money to go away with my son.

44. I now receive regular payments from the BSO of £4,500 a year, which I receive in quarterly instalments.

45. It is not a nice system, having to apply for financial assistance, but I didn't have a bad experience with the Caxton Fund.

46. When the Business Services Organisation (BSO) was set up in Northern Ireland, it was supposed to be an easier system. I have not found this to be the case and will not be applying to them again for financial assistance.

47. I have found the way they deal with applications humiliating.

48. During the transition from Disability Living Allowance to Personal Independence Payments, I lost my payments and it was at a time when I had to buy a new car. I applied to the BSO for financial assistance and the form I had to fill in was ridiculous. I was required to list all of my outgoings down to the pence. I returned the form with a few quotes for the kind of cars I was looking at and I was very quickly declined. I was not able to receive any help from the BSO with the purchase of a car. I believe that if I had asked Caxton for the same thing, I would have received help.

49. I think that the trusts and funds are very scattered and they do not seem to have any fixed system. Some people benefit far more than others. My mother

is very shy about asking for financial assistance and we have found that she has not received as much financial assistance as I have. This is despite the fact that she is in a worse position than me, as she has not cleared her infection and has recently required treatment.

50. It seems to be that if people are more forceful and fight for their payments, they get better results. I do not think that people should be treated differently.

51. I am fortunate that my employers are very lenient with my medical issues and I am permitted to work from home and work flexible hours when I am not feeling well.

52. Although I am financially secure, I do not think that I should receive any less financial assistance than anyone else and I do not believe that the financial assistance should be means-tested. We were all given contaminated blood, it should not matter what infection we have contracted, in my opinion. I think that the rules should be the same for HIV, Hepatitis C and Hepatitis B, and we should all be entitled to the same support and assistance.

53. I have also had difficulty obtaining life insurance as a result of my infection. Although Dr Gary Benson informed me that I do not need to declare my haemophilia or Hepatitis C, I have always done so and have been refused life insurance.

Section 8. Other Issues

54. A treating Consultant I have seen told me that they suspect that the advice Dr **GRO-D** gave to Haemophilia Directors was not the advice she followed herself. He said that she told the rest of the UK that the risks were low and that they could use American Factor VIII products, but she tried to use Scottish products on her own patients and did not follow her own advice.

55. As my mother was also infected with Hepatitis C, I have always had an underlying worry about her health, as I know that this could end her life early. When I was younger I did not really understand the impact of Hepatitis C, but

as I have grown older, I have become much more aware of it. She often feels lethargic and she lacks the energy to do things that I know she would enjoy doing.

56. My mother and I's haemophilia and her Hepatitis C have been a real strain on my Dad GRO-C which my mother and I believe has been due to the stress of our health conditions.

57. It is unfair that my family have had to deal with hepatitis as well as my mum and I's haemophilia.

58. I requested a copy of my medical records from the Royal Victoria Hospital, Belfast in Autumn 2018 for the purposes of contributing to the Infected Blood Inquiry. When I received my notes, these did not include any information relating to when I became infected with Hepatitis C. They do not include any details of my treatment with Factor VIII in the early 1980's, my blood test results around that time, the date of my positive Hepatitis C test or any consultations with my parents.

59. I attach at exhibit **WITN1383004** a copy of my application to the Skipton Fund in 2004 for the £20,000 ex gratia payment. The application form is signed by a Orla McNulty, a clinician from the Belfast City Hospital Trust, who confirmed that I tested positive for hepatitis C antibodies, as well as my symptoms.

60. NR I would be prepared to give oral evidence.

Statement of Truth

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

Signed...... GRO-C ....

Dated..............29/11/2018....................................