Witness Name: Craig Owen Berry
Statement No: WITN1092001
Exhibits: None
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CRAIG OWEN BERRY

I, Craig Owen Berry will say as follows:-

Section 1. Introduction

1. My name is Craig Owen Berry and I live at GRO-C GRO-C I was born on GRO-C 1982 and I have recently remarried. My wife is called Sami Berry and we have four children. I am on long term sick leave and have been for the last five to six years but prior to this I worked in IT. I am an only child and my both parents, Jeannette Anne Berry and Stephen Owen Berry are both alive.

2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006.

3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

4. I suffer from severe Haemophilia A. When I started crawling aged around 7 months old, my mum noticed that I was covered in bruises all over my body.

She took me to the hospital where social services took me away from her GRO-D. After a few hours I was diagnosed with Haemophilia and so I was returned to my mother. My Dad GRO-C GRO-C in the Navy in the Falklands War during 1982 and when he got back and my mum informed him of my haemophilia, he found it hard to deal with.

5. I was treated at both Portsmouth Haemophilia Centre and St Thomas' Haemophilia Centre where the chief consultant at St Thomas' was Dr Savage and I was also treated by Dr GRO-D. I lost trust in St. Thomas's Haemophilia Centre and as a result I moved to Basingstoke Haemophilia Centre around 2015 as I just needed a change and had to get away from everything; it was all too traumatic. In Basingstoke, I am treated by Dr Sarah Mangles.

6. I believe that I was given infected Factor VIII blood products from some point between 1984 and 1986 when I was two to four years old. I was put on home treatment from the age of four.

7. As a result of receiving Factor VIII, I was infected with Hepatitis B and Non A non B Hepatitis, which is now known as Hepatitis C.

8. My mum took me to all my appointments but neither of us were ever given any information about the risk of being exposed to any viruses before I was given Factor VIII treatment.

9. When I was about 14 years old I remember there was a phone call telling me that I had to come in for an appointment; this was the only time that both my parents came to an appointment so I had a suspicion that something was going on. In this appointment I was told that I had been infected with Hepatitis C. I think it might have been Dr GRO-D who informed me. It was a massive shock to my mother when she was informed that I had been infected with this virus.

10. I do not feel that I was given adequate information about the infection regardless of the fact that I was only 14 years old, so I did not even understand what I was being told. I also think that the information should have been provided to me earlier; there was a gap between my first positive test in 1991 and me being told in 1996.

11. I only found out that I was infected with Hepatitis B last year, when gathering information for this Inquiry, from my doctor of 10 years at St. Thomas's Hospital, Dr GRO-D. I was told that I had self cleared Hepatitis B and was never told about it.

12. I feel that face to face was the best way to tell me about the infection and so I was fine with that.

13. I was told about the risk of infecting others and so I had to sit down with my girlfriends parents and tell them about my infection and that their daughter was at risk of contracting it. I felt humiliated.

Section 3. Other Infections

14. I was not told of any other infections.

Section 4. Consent

15. I was tested and treated with my consent; however, I was not given adequate information for either.

16. I believe that I have been tested and / or treated for the purposes of research as I was one of the first people to be put on some of the new treatment drugs. I would not be surprised if my details were passed on to other people either.

Section 5. Impact of the Infection

17. I suffered significant mental effects from being infected with Hepatitis C. I walked around feeling permanently diseased. Although I was lucky to clear the infection through Interferon, no amount of telling me that I have cleared it helps me mentally.

18. One of the biggest difficulties for me was the shock when I was told of the infection. My defence mechanism was to just block out everything to do with the infection and so as a result I cannot remember much from the day I was diagnosed to about 16 years old; good and bad memories. My mind still goes blank when I think back to all this and the trauma still gets me. I just block everything out.

19. After I was told I began self harming and tried to commit suicide twice by slitting my wrists and I even jumped out of the fourth floor window in my school. From when I found out about my infection I never cared about anything. I always thought that I would die anyway so I *'did not give a toss'*. It even ruined my relationship at the time GRO-D GRO-D, I felt humiliated.

20. I have continuously been battling with severe depression and it has affected my trust in people. I therefore do not trust people easily and it affected my confidence. As recently as Christmas 2018 I had suicidal thoughts again.

21. It was horrible knowing you could infect other people. I was fearful for even hugging my parents. I distanced myself from everything and everyone.

22. I was already angry that I had Haemophilia and so contracting Hepatitis C only pushed me further down. I went from disliking everything to fully hating it. I was struggling to deal with everything and it resulted in me stopping taking my Factor VIII treatment; I hated it for giving me Hepatitis. This had a knock on effect as it resulted in me having several bad bleeds. This scandal has made me hate to take Factor VIII even now but now I just have the

occasional missed treatment, whereas before I would go weeks without it, unbeknown to anyone, and used to suffer so I would hide my bruises.

23. After I was told I took up extreme skating which was very dangerous; I would always push the limits and had little fear of the consequences. I used to go backwards down stairs and perform jumping somersaults; my fear level became non existent. I did not want anything other than to die and I felt that it would have been easier for everyone else. I became very rebellious and just acted out.

24. Drinking also became an issue for me even though I was only 14. Even after having cleared the infection, from the ages of about 17 to 21 I was drinking seven to 10 pints a night and tried to just lose myself in oblivion so I didn't have to deal with everything.

25. I was diagnosed with mild cirrhosis and was fortunate that I was quickly given Interferon as a trial drug in March 1996. I was only supposed to be on this Interferon trial for a year but I reacted so positively to it with the results that I was kept on it for 18 months.

26. However, the treatment for Hepatitis C also had a significant effect on me. The side effects consisted of feeling sick and throwing up, losing my appetite so I would be not eating as I would just become nauseated and having migraines. I suffer from a phobia of needles and so having to take these injections in my stomach was not easy. I would then feel a burning sensation from the injections and my stomach would feel like it was on fire for about 15minutes after the injection.

27. I know that I suffered more mentally from everything and last year, when Collins Solicitors announced that the Inquiry was moving along, I decided to that this was the last chance to deal with my mental state. This however did not work and as recently as Christmas 2018 I had suicidal thoughts again. I have been in regular contact with the Crisis team and have been referred to a Psychiatrist, but am still waiting for an appointment date.

28. I did not face any difficulties in accessing the Interferon treatment. I was offered it on a trial from St. Thomas's very quickly. Dr GRO-D told me that only 1% of people on the trial have actually cleared the virus.

29. I was told that I cleared Hepatitis C after the trial but the positive results started after a few months. I finished the Interferon treatment just before I started my B-techs.

30. My dental treatment was always an issue due to my Haemophilia anyway and so there was no major difference when was then infected with Hepatitis C. St. Thomas' used to do my dental work so I assume they knew about my Hepatitis.

31. My social life went straight out of the window. As soon I was diagnosed with Hepatitis C I became a hermit. My first girlfriend was with me throughout the whole of my Hepatitis C infection so I had to tell the whole of her family. I was sexually active from a young age and so this stopped when I found out about the infection, which as a teenager, I did not like.

32. Prior to my infection I was very sociable but I became the opposite afterwards and I lost all my friends. I even distanced myself from the ones that went to the same college as me as I felt that they were a reminder of my past.

33. My relationship with my parents was also affected as I distanced myself from them too. I had a lot of pent up anger and being the only child, I lashed out at them. I did not want anyone to know of my infection. My parents noticed that I was drinking a lot and I just felt that I had let them down. I used to wonder why they loved me when I was infected with Hepatitis C and had Haemophilia. I used to feel awful and just question everything. This resulted in me moving out of my family home when I was 27 years old. The only reason that I did not move out earlier was because I was in a wheelchair for a few years due to my Haemophilia. My parents built me an annex in the back of the garden and I lived there myself, so it was like my own place anyway as I was self-sufficient.

34. I never told anyone about my infection due to being worried of the stigma surrounding Hepatitis C. I therefore only told my mums sister and my grandparents. Although I thank them for not telling anyone, I think it did make things harder because it became almost like a "*dirty secret*" and was made more of an issue. The few times that I did accidently mention my infection to people, they did not want to be near me or touch me. This confirmed to me that I should not tell people due to these reactions.

35. The treatment really affected my education as I had just completed my GCSE mocks when I was told about my infection and was then put onto Interferon. I had to take so much time off school as the treatment was so rough. I therefore got bad grades and had to change the college that I wanted to apply to; where all my friends were also going. I had to go back and retake my exams.

36. I then had to do BTEC and not GCSEs and so this changed my whole life plan. I had to do an extra two years in school and make new friends. I really threw myself at these studies and used them as an escape mechanism to focus my attention. In my exams, I got a distinction which was the equivalent of A*s in A-levels and so I had my pick of university. I chose computer science at Reading University which was the best in the country for the course at that time. I could have been flying and very financially healthy. I then went to university but my Haemophilia again got worse and I had to drop out after my first year.

37. I had wanted to get my degree before my illnesses got too bad so that I could then be working on a business from home, but unfortunately I could not manage to do this. I have suffered from financial effects from not being able to get a degree and having to spend a lot of time working my way up in a job before I would just get fired anyway every five years because of my haemophilia.

38. My ex-wife had to deal with a lot as I became a mess. Every few months I would have a bad episode and this put a lot of strain on my relationship which eventually failed.

39. When I got together with my current wife, Sami, I told her about my Hepatitis C infection. I was taking opioids for pain and anti depressants. After going on a four week input programme at St Thomas's I managed to come off the opioids with the help of my wife. I got worse before I got better and my wife felt helpless as she could not do anything to help. When I would go to the bathroom my wife would be worried if I would come out again as I was just so low. She is the one who gives me my injections when I am not able to cope. We would have arguments about it sometimes and about the smallest things. I am still on anti depressants.

40. My wife has to be careful with what she says about me as she knows I sometimes do not take things well. She is very supportive and always does her best by me. She feels that what happened with this scandal and everything it has caused is horrific.

41. The doctors' tell me that I am not contagious so I do not have to tell people of my infection; however, I have no trust in them and still tell people. The doctors' still monitor me and do liver and blood tests so my mind still does not change and I still feel horrible.

42. My parents are very loving and caring but being told of my Haemophilia had a massive impact on my mother. She always wanted a big family but did not want the risk of putting another child through the same thing as I had been through.

43. My mum struggled to cope but she tried to keep it away from me. It was difficult for her to see her son injecting himself. She was a flight attendant and could not quit as she needed the money due to my dad being away. I therefore spent a lot of time with an au pair. My mum always wished she

could have been there more often. She seemed very drained from everything.

44. My dad GRO-C GRO-C He did not like to talk about it for fear of getting too stressed out but it had a huge impact on him too. He is a very hands on Dad GRO-C He is constantly worrying after me; he is concerned about my mental health and whether I need counselling and also about whether I am taking my Factor VIII.

45. My parents tried hard to hide their pain but I could see it. I was suicidal and so my mum was constantly worried whenever I was out of her sight as she thought I was going to kill myself. She lost sleep and was just living a nightmare. My dad did not like talking about any of this GRO-C GRO-C

Section 6. Treatment/care/support

46. I believe that there is a lack of mental health support as they are massively underfunded so my referral for counselling would get turned down. I was first referred for counselling during my GCSEs in or around 1996 when I had several sessions before being told that they could not help me further and I needed to see a more trained psychiatrist as my issues were too deep for just talking therapy. I do not think that these further sessions were ever arranged.

47. I also had mental health support at the Haemophilia Centre in Basingstoke when I moved there around 2015, but they started to become very difficult and would only talk about issues directly linked to Haemophilia or Hepatitis C specifically and nothing else, including any related social issues. They also said I needed to speak to my GP regarding a referral for more specialist help. However, I was never given a psychiatric appointment.

48. At the last quarter of 2018 my mental health deteriorated significantly and my GP contacted the Crisis team. Although they would come almost every day, it was always someone new and so I would end up repeating myself with different people over and over again. It was not an effective solution. Unless I am cutting myself or attempting suicide I feel that I will simply get put on the backburner as they do not have the funding to cope with the people and referrals coming through.

49. In around November 2018 the Crisis team said that they would refer me to see a Psychologist, but I am still waiting for my referral to be completed.

Section 7. Financial Assistance

50. I was in touch with the Skipton Fund from around 2005 when my mum told me about it after hearing about it from friends. They always seem to find out new information about the Fund and inform each other. Soon after I received a Skipton stage 1 payment of £20,000 and then in 2018 EIBSS took over and now I get a monthly payment of about £300.

51. The process of dealing with the Skipton Fund was fairly straightforward. I got the form from the Skipton Fund and sent it off, then I had a couple of calls and that was that. For EIBSS I had to fill out another form but they had most of my details, so it was not too bad.

52. I did not know about the financial assistance schemes while they were running so I got another £5,000 from EIBSS. As far as I am aware there were no preconditions for payment.

53. I think the Skipton Fund were very helpful and supportive; I am very happy with them. Any form of assistance is always very handy for me as I am disabled.

Section 8. Other Issues

54. This is all about justice now. It is criminal the amount of people that were infected and how everything was covered up. It affected so many more people than just those directly infected and the implications have been huge but I feel that they are just wasting time and still do not care.

55. I really feel that they are trying to slow the process down as much as possible and hope that everyone dies before anything is done.

56. People will always fight this cover up and we all want answers. It is time. People will keep fighting until the end. It is not just about me; there are so many other people. I just get on with things but some cannot. People are dying. Everyone should know what they did. They will just continue to give scapegoats.

57. I am only still in this for everyone else. It would be much easier for me to move on and say I do not care but I want to help others. I have lost friends and I cannot give up for all the other families. Everyone deserves justice.

Anonymity

58. I do not wish to remain anonymous.

59. I would like to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-C ....

Dated....26/2/2019..................