Witness Name: Alan Burgess
Statement No:WITN1122001
Exhibits: WITN1122002-4
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ALAN BURGESS

I, Alan Burgess, will say as follows:-

Section 1. Introduction

1. My name is Alan Burgess, DOB GRO-C 1958 and I live at GRO-C GRO-C Suffolk, GRO-C with my wife, Denise. We have three children; Sarah, Laura and Liam.

2. I was infected with HIV and Hepatitis C through contaminated blood products.

3. I was co infected with HIV and Hepatitis C as a result of treatment with contaminated Factor VIII concentrate.

4. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

5. I was diagnosed with mild haemophilia A in or about 1967. I had my tonsils removed and almost bled to death, and again bled heavily after I had a tooth extraction before they finally diagnosed me with haemophilia.

6. I was initially treated with cryoprecipitate. In December 1982 I had a bleed to my left calf after a football injury. I was treated at Ipswich Hospital where they initially gave me cryoprecipitate but it didn't really help; they would send me home and I wouldn't be able to walk. I was then referred to Addenbrookes Hospital where I was given Factor VIII. I was joking with the doctor as I had heard they got the blood from pigs, to which he replied there was nothing to worry about. This was my first recollection of receiving Factor VIII.

7. There is now shown at **WITN1122002** to me a copy of my treatment record from the UK Haemophilia Database.

8. There is a reference in my medical notes to me receiving Factor VIII for a tooth extraction in 1976, I believe this reference actually relates to cryoprecipitate –this seems to be confirmed by my UK Haemophilia Database records.

9. Shortly after receiving the treatment in December 1982 I started to feel terrible; I was unable to go to a New Years Party as I felt so bad. I really didn't think anything of it at the time, but in hindsight it is probably a result of my treatment and I was most likely infected at this time. This was also the conclusion of the solicitors instructed in the 1991 HIV Litigation. My Statement of Case from that Litigation is exhibited at **WITN1122003**.

10. I had several other treatments for small injuries between 1982 and 1985 but these were with cryoprecipitate. There were probably around five treatments in the years following 1982, but I wasn't really attending regular clinic appointments like I do now.

11. In 1985 I received a phone call telling me that as I was a haemophiliac, I would have to be tested for the AIDS virus. The consultant told me that I had nothing to worry about as I had only been treated with British products. I believed him and put it to the back of my mind.

12. A few weeks letter I received a letter informing me that I had been diagnosed with AIDS. I remember reading this letter in bed. I am furious that they told me the news via letter. It was so insensitive and that letter could have gone anywhere; it could have accidentally been delivered to a neighbour. It was entirely thoughtless and inappropriate for such earth shattering news to be delivered in this manner. There is now shown to me marked **WITN1122004** a copy of the original letter which I have kept all these years. Interestingly I have been unable to locate a copy of the letter in the medical records that have been provided to me.

13. I went to Ipswich Hospital a few days later. My notes state that I received comprehensive information and counselling regarding my HIV diagnosis, but this simply isn't true. They told me I probably shouldn't tell anyone about my virus but I was given no real information other than this. My notes suggest that, at that appointment on 10 October 1985, my wife expressed anxiety and concern about starting another pregnancy. This is not correct. The route of transmission of the virus was not discussed with us and we were not warned about the risk of unprotected sex or of considering further adding to our family.

14. My wife and I then went to the Addenbrookes Hospital in an attempt to get some more information about the virus, and we were seen by Dr Seaman. She was absolutely horrible. She asked why we were there as we had already been told this information. She made my wife cry.

15. My records suggest that my first blood test which showed I was HIV positive was on 05.09.1985 and I was informed of this diagnosis on 04.10.1985.

16. In April 1995 I was in the hospital when I looked at the page on top of my medical records. It stated that I was Hepatitis C positive. I didn't even know

that I had been tested. I mentioned it to the nurse who said 'oh you shouldn't have seen that'. I was told that I shouldn't worry about it too much as hopefully it wouldn't trouble me as much as the HIV would.

Section 3. Other Infections

17. I have been informed by a letter that I am at risk of vCJD. I have to disclose this when I receive treatment which has caused me problems in getting dental treatment. At one stage I had to go to a dentist in London as there wasn't a dentist in GRO-C who would go near me. Fortunately, I now have a local dentist.

Section 4. Consent

18. I was invited to Ipswich Hospital for my HIV test so I was aware that I was being tested for HIV, however, I had no idea that I had been tested for Hepatitis C.

19. My wife also required intermittent testing for HIV to which she consented to.

Section 5. Impact of the Infection

20. As I was given no real advice as to the risks of transmission, my wife fell pregnant within a few months of me receiving my diagnosis. We went to the GP who said he couldn't give us any advice, but he said he was a religious man so we should "put our faith in God".

21. When Denise went into labour, she was put in a room on her own at the end of the ward. She was miles away from everybody. We were told that we couldn't tell anybody on the ward about my HIV status or it would probably be shut down as all the patients would discharge themselves. There were yellow biohazard stickers put up in her room and Denise felt like the nurses were very offhand with her and couldn't wait to get rid of her. What should have

been a happy time for us was ruined by the problems caused by my HIV status.

22. Liam was born on GRO-C 1986 GRO-C my wife tested as HIV negative. Denise had to be tested numerous times during our marriage which was difficult for us both.

23. After Liam's birth I wasn't ill for a good few years and I tried to put HIV to the back of my mind. We lived in a little close so we made sure we didn't tell anyone, and we got on with life as normal. At that time the stigma associated with HIV/AIDS was rife and not a day went by when it wasn't in the newspapers or on TV.

24. When I was diagnosed I was a painter and decorator with my own business. After we brought Liam home from the hospital I started a job painting the outside of my next door neighbour's home. The lad who I had working for me overheard the news on the radio about Rock Hudson and AIDS and loudly stated that anyone with the disease should all be shot or put on an island. Denise started going mad, but fortunately I got her to calm down as I didn't want anyone to find out about my infection.

25. I started to suffer from recurrent chest infections and pneumonia. Around this time I was also a part of the 1991 HIV Litigation which was very stressful. This was made all the more difficult because I couldn't tell anyone about it.

26. I wasn't aware of it at the time, but my kids were having a hard time at school. As people knew I suffered from haemophilia, they started putting two and two together and assumed that I had AIDS. I also later found out that Laura was often going without lunch at school because she was too worried to accept free school lunches in case people asked questions about what was wrong with me (she was only entitled to free lunches because of my HIV diagnosis).

27. I received a motability car and I was advised to take a break from work. However, within a couple of days of having the car it had been vandalised;

someone had put a brick through the window. The police took it seriously enough and installed a camera.

28. People in our close stopped talking to us. When we returned from our holiday one time the window frames on the house had been vandalised. We had no other option than to move home and I am very glad we did.

29. It was impossible for us to obtain a normal mortgage or life insurance. Eventually we were able to obtain an interest-only mortgage.

30. My daughter Laura was really struggling at this time. She was the one who would often see me at my worst. She went off the rails and I later learnt that she was self harming and had tried to kill herself. I only learnt this at the Archer Inquiry. I gave oral evidence and she was meant to speak after me, but she broke down in tears as soon as she started talking and a friend of mine had to read the statement for her. It was heart-breaking hearing everything she went through and I feel incredibly guilty that I didn't know how much she was suffering.

31. Sarah is my eldest daughter and she dealt with my illness in her own way. We told each of the children separately about my illness when they reached the age of 11. Telling Sarah first must have been very hard on her because she couldn't even discuss it with her siblings.

32. Liam struggles to talk about it to this day. He went into a shell and wouldn't dare to tell his friends. He is only just starting to process everything now.

33. I was offered to be part of a trial to compare the effects of AZT versus placebo however I declined this offer on 20.01.1989. When I did finally start AZT treatment, I had terrible side effects. I suffered from dreadful headaches, a metallic taste in my mouth and feel extremely sick. I would also have terrible nightmares and peripheral neuropathy.

34. My wife and I split up for three and a half years in or around 1996. I was a horrible person to live with and I would go missing for periods of time. I had

lost my business, I was on drugs with horrific side-effects and I was having awful night terrors. I lost a lot of friends and it was a terrible time for me.

35. I made the decision to kill myself. I planned to gas myself in my car with a hosepipe. The police were told of my disappearance because I was on medication that was keeping me alive and I had not taken them with me. They tried to find me but it was my sister who found me in the end.

36. I ended up going to St Clement's psychiatric hospital. They started to allow me home one day at a time, and after 4-5 weeks they believed that I seemed okay and they let me home. I definitely felt better by the time I left.

37. When Denise and I split up we stayed in touch and I still saw a lot of the kids when they would come round to care for me. My wife and I remained friends in this time, and when I was in a better place mentally we made another go of it and we have been together ever since.

38. In January 2002 there were no more drugs that they could give to me. By this time I was being treated at the specialist HIV unit at Chelsea & Westminster Hospital in London. I had multiple intolerances to the anti-retroviral drugs. I was sent for for salvage therapy and my CD4 count was down to 17. I had MRSA and sores all over my body. I was told that I would have to stay in hospital. Fortunately, combined therapy has since come on leaps and bounds and I am in a much better place health-wise.

39. Over the years I have suffered from numerous serious health problems due to both my HIV and the medication that I have had to endure. These problems have included mouth ulcers, recurrent skin infections, recurrent respiratory infections and one episode of herpes zoster. This list is not exhaustive. As recently as six months ago I had to come off a drug called Truvada because it was causing damage to my kidneys. I feel that the HIV medication had played a massive role in who I have felt over the years (both physically and psychologically) and that it will continue to do so for the rest of my life given that I am on medication for life.

40. I haven't had any treatment for my Hepatitis C. I go for fairly regular monitoring of my liver but I haven't had any problems with it as of yet. A liver biopsy at Addenbrookes Hospital in 1996 showed that I did not have fibrosis and I therefore refused the Interferon treatment that was being offered to me. I was told that it was likely to be less effective in HIV positive patients than in anyone who was mono-infected.

Section 6. Treatment/care/support

41. There were support groups for homosexuals with HIV, for drug addicts with HIV, but nothing available for haemophiliacs with HIV. It was for this reason that we set up the Birchgrove Group.

42. It was extremely difficult to lose so many friends from the Birchgrove Group. We became brothers and it was so tough having to go to funeral after funeral. People would wonder why we would hug at the end of each meeting but it was because you might never see them again. I stay in touch with some of the families but you feel an element of survivor's guilt - why am I still here when they haven't made it?

Section 7. Financial Assistance

43. We had to sign a waiver to get anything from the 1991 HIV litigation. I was told that if I didn't sign it, nobody would receive anything. At that stage I believed I only had three years to live and I needed that money for my family as I was unable to get life insurance.

44. I received the Stage One payment from the Skipton Fund.

45. I used to just receive monthly payments from the MacFarlane Trust but now I also receive a monthly payment as a result of my Hepatitis C. This is the first time I've ever really been able to put some money aside.

46. I have been investigated by the DWP on numerous occasions because I am on sickness benefit. I have even been told that they are going to interview me under caution. They have gone through all of my finances with a fine-tooth comb, and also my son's bank information when he was living at home. Sometimes you are lucky and you get a nice person coming round, but other times it's like they have sent round the Gestapo. They have made my wife cry and they act like they are out to incriminate you.

47. The DWP also investigated because of my inability to get a proper mortgage with any life assurance. I was unable to do so because of my HIV status. I was forced to get an interest only mortgage and, as a consequence, had to save up to pay off the capital sum at the end of the mortgage term. I therefore went over the savings threshold for the DWP and it didn't matter how many times I explained the situation to them, I was still regularly investigated. This brought with it undue stress for both me and my wife.

48. I would much rather be working than claiming benefits, but I have been infected with these viruses and I am not able to work. That isn't going to change so I don't understand why they are so insistent on questioning me so often.

49. I fell ill when I was on holiday last October and had to pay medical bills of £220 as if I had claimed through my insurance the excess would have been even more expensive. EIBSS refused to compensate me on the basis that they are no longer meeting "health related costs" for those who are HIV infected. I have been trying for months to get this money repaid but they have refused. If they aren't paying out for HIV related illnesses then what are they even doing? Travel insurance is so expensive for us and it is something that EIBSS are terrible at helping with.

50. I feel that this is all part of the suggestion that HIV should be downgraded because it is now considered a "treatable" illness. This has not always been the case. The few of us who were infected in the 1980s and have lived through taking all the experimental drug treatments for our illness have had an

entirely different experience and outcome from someone who might be diagnosed as HIV positive today.

Section 8. Other Issues

51. The Government is happy to try and brush us all away. They don't understand that although HIV may be manageable if you are infected today, for those of us who were infected in the 1980's the damage has already been done. We have had to go through all of the experimental treatments with horrendous side effects. We shouldn't have to keep fighting for everything.

52. I was a founding member of the Birchgrove group and I spent many years sitting on the board of the MacFarlane Trust; as such I have much more information to provided that is not covered in the remit of this statement.

53. Pursuant to paragraph 2.9 of the Notice of Determination in the Award made to my Solicitors preparation of this statement does not cover investigative work. I would like to give evidence on the matters set out at Paragraph 50 above and I am unable to do so in this statement.

Anonymity

54. I do not want to be anonymous.

55. I would like to give oral evidence, but I will be away from mid-April to mid-May 2019.

Statement of Truth

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

Signed. GRO-C

Dated 25-2-2019