Witness Name: Denise Burgess
Statement No: WITN1119001
Exhibits: 0
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DENISE BURGESS

I, Denise Burgess, will say as follows:-

Section 1. Introduction

1. My name is Denise Burgess, DOB GRO-C 1959 and I live at GRO-C Suffolk GRO-C with my husband, Alan. We have three children.

2. My husband, Alan Burgess, DOB GRO-C 1958, was infected with HIV and Hepatitis C from contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my husband's 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 Affected

4. Alan was diagnosed with mild haemophilia A when he was a child.

5. Alan and I met at senior school when I was 13 and he was 14. We have now been married for 40 years. I was always aware of his haemophilia but didn't know anything about haemophilia other than what he told me as I had not come across it before.

6. Alan was initially treated with Cryoprecipitate and we usually went to Ipswich Hospital if Alan had a bleed, however he was only a mild haemophiliac so lived a very normal life; he played football and didn't let his haemophilia hold him back. Occasionally he had to be treated at Addenbrookes if he required more specialist treatment.

7. He first had Factor VIII at Addenbrookes Hospital in December 1982 after Ipswich Hospital had failed to successfully treat a football injury. We were not really told anything about the new treatment.

8. Shortly after this we started to see things on the news regarding HIV and the risk to haemophiliacs. Alan's mother and I both separately phoned Ipswich Hospital to get more information, but we were both told that we had nothing to worry about because Alan had only ever been treated with Cryoprecipitate.

9. In 1985 we received the letter telling us that Alan had been infected with HIV, although as we had such little information about what the virus was we weren't particularly worried.

10. Alan found out by reading his medical notes in the hospital that he had also been infected with Hepatitis C. When he asked a nurse about it, she said something to the extent of 'oh you shouldn't have seen that'.

Section 3. Other Infections

11. Alan has been told that he may have been exposed to vCJD.

Section 4. Consent.

12. Alan was told by the hospital that he would need to be tested for HIV; however he had no idea that he had been tested for Hepatitis C and as such could not have consented to such testing.

Section 5. Impact

13. I fell pregnant with our third child, Liam, because Alan was in denial and would not use contraception. I also believe that it may be due to the mixed messages we were receiving from the medical 'professionals'. I remember after we had sex he said 'well that's number

3'. We went to see my GP for advice, who was a religious man and told us that we should just put our faith in God.

14. When I went into labour I was put in a completely separate room and was not allowed to see anyone else. I was in a room all on my own for 7 days with my baby. I now understand that due to the fear at the time there would have been pandemonium if other people found out about my husband's HIV status on the maternity ward.

15. **GRO-C** I had already been tested and was negative, and continue to be tested intermittently with the indignity of sitting in our local sexual health clinic.

16. It was only slowly that Alan's health started to deteriorate and he would take increasingly long periods off work. He was a painter and decorator by trade. When I came home from the hospital with Liam, Alan was painting our next door neighbour's house. I overheard his colleague telling Alan that everyone with AIDS should be put on an island and shot. I was furious but Alan just had to stand there and listen to it because nobody knew about his infection.

17. He suffered from horrible moods and it was tough to cope with as a family. We eventually had to tell the children what was happening. I think we told the girls when they 11 and 13. It was a very difficult age for having to deal with such information and having to keep it a secret; it was like we were sending them mixed messages by teaching them right from wrong whilst also telling them to keep this secret. It is no wonder that all of my children have had, and continue to suffer from mental health problems.

18. Alan's health continued to deteriorate. Whenever Alan worked he would get ill, so he ultimately had to choose between his work and his health; fortunately he gave up work.

19. When Alan gave up work things became increasingly difficult. Alan was on AZT and at times he would go AWOL. He would go up the stairs in one mood and come downstairs a different person; I used to call him Dr Jekyll & Mr Hyde. It was a horrible time for all of us as a family. It was obviously difficult for Alan as he was the one having to go through the illness and mental effects, but it was extremely tough for us a family having to cope with his mood swings and behaviour. Although Alan was never physically aggressive towards me,

he was emotionally abusive. There were also times when he threw furniture. Emotional abuse wasn't recognised back then the way that it is today.

20. I couldn't understand everything that was happening; our family was being torn apart. I knew we couldn't continue living as we did as we had been walking on egg shells for so long. I couldn't understand Alan's contempt for me.

21. One minute I was a wife and the next minute I was a nurse; all whilst also having to be a mother. Having so much to worry about was incredibly stressful and really messed with my head. I think I developed a bit of OCD as cleaning was the only thing I had real control over. I became obsessive over making sure that everything was clean and I would flip if the kids left a glass or a plate on the side.

22. Alan was admitted to a mental health hospital which was a particularly difficult time for us. It was another secret that I and our children had to keep. The pain and discomfort of keeping this secret was unbearable.

23. Things got really bad between me and Alan, and we ended up separating for 3 years. He initially threw me out of the house and I was forced to live in a women's refuge, whilst the kids stayed home with Alan. Alan then decided that he could no longer cope with the children so rented a place of his own and I went home to look after the kids. That meant that they spent a lot of time going to their father's place to care for their dad as his health was so bad.

24. This all happened during Liam's formative years as a young teenager and it had a huge impact on him. I have only just found out he didn't tell a single person about his father's situation until he was 28 years old. It is absolutely dreadful that he has had to keep it bottled up for so long and felt the need to keep it such a tightly guarded secret.

25. Things were incredibly difficult for our children. We found out a few years ago that our middle daughter would not take her free school meals because she was ashamed. Sarah had one friend at school who she confided in, but she went and told the other girls at school. The girls would also be asked if their father was a drug dealer because he didn't work but seemed to have money. Laura got involved in drugs GRO-C. I feel so guilty that I didn't know what was happening and that I wasn't able to help her.

26. Alan and I started courting again after some time apart. I didn't like the person he had become and if he hadn't changed we wouldn't be together now, but I love him and wanted us to work. It still isn't easy, but Alan knows how to cope with his illness now. He knows when to stop, he knows when he isn't well and he knows how to manage his illness. However, the only thing he isn't able to cope with and manage is his own head and his mental wellbeing.

27. Alan told our oldest grandchild about what happened GRO-C GRO-C There are another 7 grandchildren who can see that their grandfather is ill but don't know what is wrong with him, and my children are eventually going to have to sit them down and explain it to them. It makes me feel so guilty that they have to have such a horrible conversation with their children, and have also had to have this conversation with their partners over the years.

28. Alan has made it to 61 years old. He was 27 when this happened, and for all of those years illness has been a huge part of our lives. It became easier to isolate ourselves than explain to people what had happened. He has had to put up with years of being told that he wouldn't survive. At first they said he only had 2-3 years to live; then it was "he won't see 40" and so on.

29. We have also been stigmatised by having to claim benefits. It was humiliating having to bring proof of income support to every single dental appointment. Our neighbours were angry at the fact that neither of us were working and they classed us as scroungers. Alan had a motability car but they just saw that we had a brand new car and were not working. We ultimately had to move house due to fat being thrown over our windows and our car being vandalised.

30. I have never been able to do what I wanted to do because I have had to be Alan's carer. I worked in an office for a short period of time and I really enjoyed it. However, the fact I was working in an office actually meant that we were worse off financially, but Alan didn't tell me this because he could see the positive impact it was having on me.

31. Alan continues to get extremely tired. We don't know whether it's the HIV, Hepatitis C or his medication but he isn't able to do much. It is always a worry when he is starting new medication as we don't know how he will react or what side effects he may be faced with. Some of his medication has been so toxic that it has probably been worse for him than

having no treatment. In my opinion, the mental effects on Alan have been worse than the HIV virus itself.

32. Alan was banned from America for a period because of his HIV status. We had had to declare this when we took the kids to Disneyland after receiving the settlement money in the early 1990s. When we returned to America more recently we were both pulled aside by airport security because his HIV status had raised a flag.

33. I often think what Alan and I would be doing and what our lives would be like now if none of this would have happened. We still dream of buying a villa somewhere hot and going away somewhere nice for 6 months of the year, but even nice thoughts and ideas continue to be tainted by the scandal. Alan and I have had a trip to Australia booked for 2 years now, and we wanted to just go away and forget about everything. However, the Inquiry meetings will now be happening whilst we are away which means that we will have to check what is happening at the Inquiry every day of our trip. There is no escape.

Section 6. Treatment/Care/Support

34. I have never had counselling regarding Alan's illness.

35. Alan has had several bouts of counselling. I think Alan and all of the survivors really struggle with the fact that they are here and so many of their friends are not. Alan had his manhood taken away at 27 and now that he is 61, he deserves it back. His illness has taken away his ability to support and protect his family, both financially and emotionally, and he feels like he has failed.

36. When I asked the haematologist at Addenbrookes about the possibility of having more children, she looked at Alan and said 'he looks okay'. I can't imagine professionals talking like that now.

37. The care has improved massively but when Alan was at Ipswich Hospital he was being treated by a chest physician named Dr Hall instead of a HIV specialist. Alan would read a lot about the virus and new treatments available. On when occasion when Alan tried to discuss this with Dr Hall, he said 'what Mickey Mouse comic have you read that from?'.

38. When Alan was first diagnosed we went to Ipswich Hospital to see Dr Edwards to ask for more information about HIV, however she did not tell us anything about the virus. We then booked an appointment with Dr Seaman at Addenbrookes Hospital. She was very aggressive and insisted we had already received counselling about his illness, whereas in fact we had received little/no information and no support.

Section 7. Financial Assistance

39. We were made to sign a waiver to receive money from the 1991 litigation. We were told that Alan would only have 2-3 years left to live and were also told that if we didn't sign it then nobody would receive a penny, so we had no other option than to sign. When Alan received the lump sum, he spent part of it on a family holiday to Disneyland Florida for what we thought would be our last family memories before the illness got to him.

40. I find EIBSS and the previous financial schemes degrading. We are constantly questioned and assessed regarding Alan's illness in order to keep on receiving financial support. It often feels like an interrogation. When Liam lived with us they went through all of his finances and assessed the money he was earning from his part-time job. Liam was still at school and any money he earned should not have been taken into consideration when assessing Alan's benefits.

41. People affected by this scandal should be able to have their own money without having to feel like they are begging for it.

Section 8. Other Issues

42. We all know that this is our last shot. People are desperate that this won't be another 'Archer' or 'Penrose' and that we will get the justice we deserve. I am 60 years old now. I want to carry on my life how I want without having to worry about fighting for justice and when the next Inquiry will be. They need to get it right this time and give us the closure we deserve. I worry about the mental and physical effects on those infected and affected if this were to be another whitewash; the Government could have even more blood on its hands.

43. I want reassurances that whatever money Alan is receiving will be guaranteed for the rest of his life, without the need for constant check-ups and assessments. We are constantly worried that they could change the money tomorrow and we will be left struggling. When

Alan has received lump sum payments his concern has always been what would happen to me if he died; particularly in the early days when we had three young children and he was told his HIV was a death sentence which would kill him within a few years.

Anonymity, disclosure and redaction

44. I do not want to be anonymous.

45. If the Inquiry wants to hear from me then I would be prepared to give oral evidence provided it wasn't televised.

Statement of Truth

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

Signed GRO-C

Dated......10th.......APRIL....2019....