Witness Name: Rosemary Elisabeth Buggins-Allsop
Statement No.: WITN5512001
Exhibits: None
Dated: 7 January 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ROSEMARY ELISABETH BUGGINS-ALLSOP

I, Rosemary Elisabeth Buggins-Allsop, will say as follows:-

Section 1: Introduction

1. My name is Rosemary Elisabeth Buggins-Allsop and my address is GRO-C GRO-C and my date of birth is GRO-C 1988.

2. I live with my husband, Spencer, and our three children who are five, three and one month.

3. I provide this witness statement in relation to the impact of contaminated blood on me and my family. My brothers were all diagnosed with Haemophilia A. My brother Richard was infected with HIV and died on 13 May 1986, before I was born. My brother Jonathan was infected with HIV and Hepatitis C and my brother Edward was infected with Hepatitis C.

4. My mother, Elisabeth Mary Buggins, has also provided a witness statement which can be found at WITN1021001.

Section 2: How Infected

5. As a child I had quite a lot of knowledge about haemophilia. I wanted to understand why my brothers were injecting themselves at the breakfast table and we were going to the hospital regularly. Fortunately, my family (particularly my mother) were open about the illness and what the consequences were.

6. It was a very normal thing for me to see my brothers using butterfly needles. It was only when school friends staying over were surprised or squeamish about it that I thought much about how unusual it must be.

7. When their treatment was moved to St Thomas's in London, I would have been about six years old, I remember it being a bit of a treat whenever I went with them. My mother tried to make it into a day trip for us and we would go on the Tube and then go to the hospital for a while and then we would visit places such as The Tower of London. I think my mother did this to make it an adventure for me and so the day was about more than medical interventions for my brothers.

8. I had genetic counselling when I was 16, as soon as I was legally allowed to. I had asked for it when I was about ten years old because I was so aware of what it could mean and I was told "*You can't ask for it, we can't give it to you when you are of an age where your parents are responsible for you r medical care and they can't ask for it either. You can only have it once you are legally entitled to make your own decisions regarding your healthcare*". It seemed unfair that I had to wait, and I thought it was irrelevant whether I or my parents had responsibility for my medical care considering it was information I would want to share with my family anyway. It was either on, or shortly after, my sixteenth birthday that I went to the GP and asked for the genetic counselling to find out if I was a carrier. I found out that I was not a carrier.

9. I knew that there were things that my brothers had to be more careful about, but they were both encouraged to live normally and not wrap themselves up in cotton

wool. I did not see their haemophilia as a disability. If you love someone you just take them as they are. I grew up with it and that was just how things were.

10. I am not aware of the blood products that my brothers received. I remember being told that they had Prophylactic Factor VIII when they were at St Thomas's. I remember being told that it was better than what they used to have, but it was not something that was ever explained to me. My mother provides information in relation to this in her witness statement [WITN1021001], as well as information in relation to advice given and how they were informed my brothers had been infected.

Section 3: Other Infections

11. Please see my mother's witness statement for information in relation to other infections [WITN1021001].

Section 4: Consent

12. Please see my mother's witness statement for information in relation to consent [WITN1021001].

Section 5: Impact

13. My parents and brothers had always been very open with me in relation to their haemophilia and the treatments they were having whilst I was growing up. My parents did not hold back and believed that if you were ready for information, they would tell you. However, despite how very open they were about the haemophilia, I did sense growing up that there was something else that was not spoken about. I only suspected that one of my brothers had been infected from piecing together snippets of information and bits of overheard conversations. Most of the facts of what happened to my brothers I have only become aware of recently when

reading my mother's witness statement. I know that my parents and brothers were trying to protect me by not telling me, but that was not the effect that it had on me.

14. I know nothing about any of the consultations they had, when or how they were infected. I knew, by the time I was 8, that Richard (who had died before I was born) had been infected with American blood products, although I don't remember becoming aware of it. I asked questions about his death. I also went with my mother to events where she discussed Richard at medical schools for example. When I was about 12, we went to visit the couple, Rod and Joan, that my parents had stayed with when there had been extremely unpleasant media attention regarding Richard's death when it was made public he had been infected with HIV. I saw that they were extremely important to my parents and brothers, and I must have asked why. My mother then explained the distressing circumstances surrounding the media attention after his death in 1986 and how much staying with Rod and Joan had helped them. I think my mother felt more able to talk to me about Richard than my living brothers because his life was over and there was not the same perceived risk to him from public exposure.

15. Growing up I knew that Jonathan was more prone to illness. When he was ill it was noticeable. I can now rationalise this as being as a result of his immune system being suppressed. I remember returning from school one day, when I was around 10 years old, and my mother was on the telephone to the doctors at St Thomas's in London. I remember she was crying, and she looked terrified. She took me to stay with my grandparents on my own and my grandparents were taking me to school every day. It was not normal for me to be staying with my grandparents outside of school holidays. and I was very aware that something terrible was happening. My mother told me that Jonathan was very ill and she was going to go and stay with him while I had a lovely week staying with Grandma and Grandad. I wanted to talk to my mother whenever she rang my grandparents. I was so worried about her. I am very sensitive to other people's emotions and find it very difficult not to feel pain if someone else is in pain. I was even more like

that as a child. Jonathan had pneumonia and my mother had seen people who had been diagnosed with HIV die from the same pneumonia (PCP) and she thought that this was likely to be the end for Jonathan too. Jonathan would have been around 18 years old at the time.

16. There were moments of real fear for me. I often thought that someone else was going to die and how would I deal with that. I still have that fear even though I now have the benefit of a broader understanding of things. It has carried through to my parenting, and I am completely irrationally scared of my children experiencing the trauma of the loss of a sibling and I feel the need to be aware of how to help them. I cried about Richard dying many times, even though I had never met him which I still cannot explain. It seems nonsensical that you can love someone that you have never met and for them to be so important, so much a part of who you feel you are. There are memories and pictures and lovely stories that my family have of the kind and lovely person he was and so he very much felt like a part of my family, even though we were not here at the same time.

17. My parents have a big photograph up on the wall of the five of them before I was born. They did not talk about Richard a lot, but the memories they shared are really special memories. I had known from a young age about his brain surgery as an infant and the resulting disabilities. I knew how disabled he had been and that he had hardly ever walked and that every time he then learnt to walk, he would have another bleed and would have to stop and then learn to walk all over again. He hardly ever spoke, but one of the things he did say was "*Daddy, come and play*". I never knew him, but because genetics plays a big part, I did feel as though I shared something with him as my sibling.

18. Although it was nice to hear the stories, as a child it sometimes felt very much like that was the family and Richard went and I was an extra that sometimes was resented. I know this was not the case, just how I sometimes perceived it as a child. I felt envious that I could not share in those memories. I also felt guilty

because it was my belief that if Richard had not died, I would not have existed. I felt a lot of guilt and pain and a lot of confusion.

19. One scary memory I have is from when I was around 11 or 12 years old. It was the first time I had heard anybody else talk about HIV and it was on Children in Need and they talked about people getting HIV, then AIDS and then dying an extremely unpleasant death. I did not know for sure that either of my living brothers had HIV, but I had an idea from hints and conversations at home that I had overheard, such as Jonathan's life expectancy and the fact that he made it past 18 years old and the doctors never thought he would. Hearing that this was the path anyone with HIV would end up on was terrifying.

20. I was a perceptive child and I had picked up information and had asked questions because I was trying to make sense of it. I remember thinking to myself '*Right okay, so by the time I'm 30, I might not have either of my brothers anymore*'. These were genuine thoughts I had in my childhood, and I already knew I had lost one brother, and, although he died from a blood clot on his brain, HIV is listed on his death certificate.

21. I was 10 when Jonathan left home to go to University and Edward left for university when I was 12 or 13. There were times when my brothers were at university when they were really ill, and I had absolutely no idea because of the secrecy around it. If they did talk about it, they only talked to each other, so the four of them would talk about things, but did not include me.

22. I felt as though I was not part of the core of my family and that was how I felt certainly until I was in my 20s. Even now my brothers have had treatment for their infections they have not really told me about it. They may say something in passing and I will have no idea what they are talking about. They may have assumed that I knew more than I did. To a certain extent it is habit after having hidden so much for so many years. It does mean that I still sometimes feel like an outsider. If my family do something together without me, such as a weekend

away or trip, I still feel triggered by it. I feel sad and rejected deep down even though I know I have not been. It is a physical reaction rather than a cognitive one.

23. I know that the intention had been to protect me when I was younger. In particular from their experience when Richard died which my mother has spoken about in her statement. My family had to move away from home for a while to get away after what the press had published about Richard's death. It was horrendous for them.

24. There have been points in time when little bits of information have been fed to me; however, I did not have the whole picture until last year when I read my mother's witness statement. At that point lots of things started to make sense to me. I think my family have become adept at putting on a brave face and suppressing the painful things that have not been talked about. We are a close and happy family. Partners have always said that my family is wonderful and very welcoming, which they are. However, if you do not talk about these things, or you feel you cannot talk about them, then they get pushed down and it gets worse until there is no way to broach it. A certain amount of this is because we all care very much about each other and, at least from my perspective, do not want to upset each other or for other family members to feel blamed for how we feel about what has happened.

25. When I was 14 or 15, we were learning about haemophilia in biology and the teacher had also mentioned HIV. I do not recall what the link was, but I said in the lesson "*Is that why my brother's HIV positive?*" to which the teacher answered, "*I don't know*". I had not been told that one of my living brothers had HIV at this point, I think I had just absorbed the information. I did not know which brother it was, and I had thought it was Edward. The teacher never mentioned it to me again, but my mother was then called into school by my head of year and asked, "*Is everything okay at home?*" because they had assumed there was a problem they needed to be aware of. I know my mother was frustrated by the

way she was asked the question, as though it would somehow affect the staff or students at the school.

26. After that my mother then had a conversation with me and asked why I thought Edward was infected with HIV. My mother told me that Edward was not infected with HIV and the conversation did not go any further. It was quite a while later when I found out that it was Jonathan who had been infected with HIV.

27. I found out about Jonathan's HIV infection when I was 16. I remember talking to my mother about getting a job during my gap year to earn some money. I wanted to earn enough money to buy a house when I went to university. I had thought that this was what Jonathan had done. He had worked for GKN for a year and then when he had gone to Cardiff University, he bought his own house. I naively thought, "*if I work for a year I'll have enough for a deposit for a house!".* My mother had to explain to me that he was able to buy a house with the money he had received from the court case in the early 1990s because he was HIV positive, rather than money from working. I remember we were sitting in a café in a shopping centre and my reaction was "*Oh so it's Jon not Edd! Oh okay, right*". That was the first time I knew factually that Jonathan had been infected with HIV.

28. I do not recall ever being told that Edward was infected with Hepatitis C. Although, I was already pretty sure that they were both infected with something.

29. I recall Jonathan applied for a four-year master's course at university rather than a three-year bachelor's degree. He finished at the end of his third year instead and I was told that he was not well enough to continue for the master's. At the time I did not understand quite what that meant, but it was something related to one of the medications that he was taking to try and get rid of Hepatitis I believe.

30. Both of my brothers received treatment for their Hepatitis C. I remember Edward being on a trial drug to help with something that had made him very ill. I remember that he was not allowed to drink alcohol for a year as part of taking the medication, which the family joked about at the time as he was at university. At the time I did

not know that this medication was for Hepatitis C and thought it was to do with his haemophilia. I do know that he had some very severe side effects from the medication, and I do know it affected his mental health. I remember him being less patient, more tired and more irritable. Edward seemed to me to be more prone to extreme mood swings than others, but I thought that went back to Richard dying when he was so little and counselling not being available.

31. Being a mother myself of a four-year-old last year (the same age Edward was when Richard died) has made a lot of these things more real because I can now imagine things from a mother's perspective. I could sense the pain, grief and embarrassment of my mother. I think my mother feels a certain amount of irrational guilt too because the haemophilia came from her genes. I fell down the stairs with my son when he was six weeks old, he flew out of my arms and I screamed. The first thing that went through my head was what had happened to Richard and his bleed on the brain, which is ridiculous because I know I am not a carrier, but for a second I felt such strong fear and imagined something similar happening to him.

32. I cannot help but associate things that are happening to my children to things that happened to my brothers, even though there is no chance it is going to happen to them. This has not helped with my anxiety and has affected my trust in the medical system. Although, I do feel I am more determined to make my own decisions and insist on giving informed consent rather than blindly accepting others' decisions.

33. There were some obstacles to my brothers' obtaining treatment. I remember having to move from Birmingham Children's Hospital to St Thomas's because Dr Hill was no longer willing to treat my brothers. I remember my mother's relief when they finally secured treatment from St Thomas's and how happy they all were that my brothers would be receiving prophylactic factor VIII. I was told this would make their lives better, but I don't think I understood beyond it requiring fewer hospital trips. I remember Edward being able to undertake a trial treatment that Jonathan

was not suitable for due to having HIV. I do know that Edward had undergone a second treatment for Hepatitis C and then following that he had a third, which did not have the side effects he had suffered previously, and he is now clear of Hepatitis C.

34. Our family belonged to the Haemophilia Society and every year they would run a trip for haemophiliacs which involved swimming and sports. My brothers would attend these trips and there were coaches who kept an eye on them so that they did not injure themselves. I would go away with my mother and father the same week as a treat. By the time I was old enough to remember, we would go to France most years and I have very fond memories of our family holidays. There was one holiday that I was not allowed to go on when I had chickenpox and I had to stay at home with my grandparents. My mother had told me at the time that the hotel would not allow me to stay there, but I later discovered that she had been worried about Jonathan getting chickenpox as it could have made him seriously ill.

35. I do not recall experiencing any stigma directly relating to my brothers, although I have in relation to people being ignorant of HIV positive diagnoses in conversations we have had. There was one instance that was extremely uncomfortable for me. I at my boyfriend's home when I was around 17 or 18. His aunt was a special police officer. She had been talking about drug addicts and I was slightly uncomfortable anyway because of the way she was talking about them. She then started talking about them possibly having HIV and that it was dirty and disgusting. His family were passing agreement, the way that people do in a conversation, and I remember being so furious and not knowing how do deal with it. I am not very good at expressing myself when angry and I get very tense and I overwhelmingly need to cry. I was not able to marshal my thoughts into any kind of order to correct her misconceptions. I could not stop myself crying so I had to leave the room. I sat in another room shaking, crying and thinking "how can I put her right?".

36. I do think that it is only recently that people have been more accepting of those who have an HIV positive diagnosis. I have heard people comment "*Well, it's all gays, isn't it?*" or "*it's people who are too promiscuous*" or suggest only drug addicts get it. It has also been said in my hearing that those infected "*deserve it anyway*." How could one respond in that situation? I did not feel free to say "*Well actually, my brother is infected from NHS treatment, and he's had it since he was a toddler*". Once I was aware of the press coverage surrounding Richard's death and the horrible things that were said about my family, I was acutely aware of not 'exposing' my family to the thoughts and comments of unsympathetic people. I did not want to be responsible for any repeat of that experience. I have witnessed the suffering and the pain that my brothers and parents have been through. It has been difficult not knowing how to advocate for them when people are unpleasant and say something to me about people with HIV. I want to advocate for them, but also, I do not want to let anyone know because it is not my information to share. I hope I would be better at doing that now, but in the past I was not able to stand up to these injustices in the way I would have wished.

37. There was one occasion when I did say something It was when I was at school and in the biology lesson I have referred to above. We were around 14 or 15 at the time. One of the girls who was sitting on my table told everyone in my class that if my brother had died from HIV, the only way he could have contracted it was if my father had sexually abused him. Richard had died from a blood clot in his brain, not HIV/AIDS.

38. This is the only time I have found it impossible to forgive someone because it was such a malicious and cruel thing to say. She said various other things to do with HIV and my brothers, including that I was dirty and might be infected as well for all they knew. I was so angry that I wrote in the back of my close friend's book "*I hate [this girl], she's horrible*". I wrote three or four sentences about how horrible she had been which was really cathartic and, although an immature way to deal

with it, if it had been left there it would have probably been fine, and I would have forgotten about it.

39. However, what I had written was shown to her and it was then taken to my form teacher. She told me she was disappointed in me and that it was an awful thing to do. I was sent to the head of year who really laid into me. I sat in her office shaking and crying which she saw as me being sad that I had been found out. I had not specified any of the things that had been said in my writing and, therefore the teachers were unaware of the context. I was so angry that I was being punished for saying she was horrible, but she was never spoken to about the cruel things she said about me and my family. I was so angry and upset at the injustice that I could not find the words to explain to the teachers what this girl had done to me. The head of year had said *"I can see that you regret it and I trust you won't do anything like this again because I'm sure you don't want us to call your family in, do you?"*. Obviously, I did not want her to call my family and subject them to the things that she had been saying about them. I was trying to protect them.

40. I would still like to tell the teachers the real story so they could understand the effect that the incident had on me because again I felt I was not trusted. I remember that Edward had picked me up from school after this and I was still crying. He asked me what was wrong and looked intent on marching into the school to try and sort it out. I had to tell him it was nothing and instead internalise it. I did not want him to have to hear what the girl had said. Thankfully my other close friends did not treat me any differently afterwards, although there were some whispered conversations and uncomfortable questions from other class members.

41. I cannot comment on the extent to which being infected has affected my brothers' mental health. However, I have witnessed some of the effects of emotional and mental health issues. For me, it has fundamentally affected my confidence in who

I am and how I have relationships with other people. I do not remember feeling worthy in any relationship with anyone. It is very difficult to explain. My family not sharing information with me made me feel as though I was not worthy of being trusted. I was not part of their inner circle. It felt as though I was not quite good enough, which obviously is not what they intended. This all happened when I was so young that I am unable to separate it from who I am today because my fundamental development happened while I had these isolated feelings. I have done cognitive behavioural therapy and have tried to separate it out, but it is still deep down in a place I have not been able to access

42. My brothers have both struggled with their energy levels and, thus the ability to hold a job. Jonathan is extremely bright and could very easily have been a big boss at a major company. I believe he was offered a very good job which he had to turn down because he knew he would not have the energy to do it. That obviously has had a significant financial impact too. Jonathan is still not able to work. I do not think it is likely that he ever will because it would be too emotionally and physically draining. Edward also suffers from periods of extremely low energy. How much of it is psychological and how much is physical I do not know, but I believe it results from their treatment and the emotional impact of the stigma.

43. It certainly affected them both during their university educations. Edward did not achieve what he was capable of in his degree; he got a 2:2 instead of a 2:1 and he has always believed that was due to the Hepatitis treatment he was receiving which gave him horrible side-effects and so he was not able to fulfil his potential. Neither of my brothers has achieved all that one would have expected of them had they not been infected.

44. As a result of this, I feel that there is extra pressure, entirely self-imposed, for me to achieve everything I possibly can. It is illogical and I cannot articulate the reasons for these feelings; it is just another deep-seated feeling that I think partially stems from guilt that I am not subject to the same constraints.

45. I graduated from the University of Bristol with my PhD in Musicology in 2015. I had worked during some of this time on the local councils IT helpdesk. After a brief job in event management at a hotel, I got a job at the University of Birmingham working for a research centre as their conference and events administrator. It was an oppressive working environment and I left to have my eldest child.

46. Therefore, I do not have a great deal of experience and I have applied for jobs and not got them due to my lack of experience. I applied for graduate schemes and, although I have my PhD and bachelor's degree, and had passed all of their metrics, I was rejected because I did not have the required A level grades. I was devastated.

47. In some way having children has been an excuse for me not to put myself out there. Whilst we cannot afford to do a lot of things, we can live on my husband's salary and that is what matters. My children get the attention that I feel they need. It also does mean that I do not have to expose myself to rejection.

48. I went to university for seven years and my best paid job had a salary of £21,000. Although that is not a bad salary, when compared with what my contemporaries at university were earning (£40,000 plus), it felt a poor return on investment. I said to my mother that I spent all that money on an education and still have significant student debt and that it had not been worth it, but she reassured me that it is also an investment in my children's future which made me feel a lot better about myself.

49. I do feel that no matter what I achieve, it is never good enough. I thought obtaining my PhD would make me feel better about myself, but it did not because I did not consider I had done it as well as I should have. It has also affected my confidence when applying for jobs. I think to myself "*Am I good enough to do that? Will they want me? They probably won't want me because of A, B and* C." I have a fundamental lack of self-belief and self-worth.

50. I find it very difficult to push myself because when I tell myself I need to do better I also have a nagging feeling of nobody really wants me. I have found it quite difficult to put myself out there and risk that rejection. If there is any criticism levelled at me, no matter how minor, I physically feel like crumpling and I find it very hard not to let my emotions take over.

51. It has also been very painful watching my family suffer. I remember seeing my mother cry and asking her why and she said "*Oh, I am just sad*". I know how that feels. I do that and it is because so many emotions have built up and need to have a good cry as a release.

52. As a child I always knew more than the family realised. When I was two or three years old my mother used to take me with her when she was holding talks and she used to talk about the boys and about Richard. She held talks at Birmingham University until she felt it was no longer appropriate because my friends were starting to attend the University, and several had been in the audience during one of her talks.

53. I remember wanting to help a lot and wanting to make the pain go away but not knowing how to help. Not being able to help, when that was all I wanted to do, was really hard. I expect the same could be said for the rest of my family too. You cannot protect people from difficult things as much as you might want to.

54. I lie awake now and worry about what would happen if one of my children died. I also remember lying awake as child trying to work out what I would do if I lost either of my surviving brothers and how I would be able to help my mother and father. It was almost like having a plan of action, just in case. No child should expect to outlive her brothers that much. In the natural course of life I will outlive my brothers, they are six and eight years older than me, but there is a fear that my children might lose their uncles.

55. I know that my family did not realise the extent of what I had figured out about their medical history or how much of the emotional trauma I had picked up. Some of it we have only discussed since the Infected Blood Inquiry started and there is still a lot we do not realise about each other's experience. I do not blame them for not telling me, but I can now appreciate the negative impact their experience has had on how I have developed my sense of myself and the world. I have a lot of hurt, sadness and anger about what my parents and brothers have had to suffer.

Section 6: Treatment/Care/Support

56. I am not aware that my brothers or my parents were offered counselling at any point. I have certainly not been offered anything. I do know that Edward has talked to a counsellor, which was at his instigation. I am not sure whether Jonathan has sought counselling. Any counselling received has been because they have gone and looked for it, rather than it being offered to them.

Section 7: Financial Assistance

57. I know that Jonathan receives some sort of benefits although there has been at least once when he was concerned that they were going to be removed if he was not classed as disabled any longer. He also has a mobility car. Jonathan also had the in court settlement which he used to help buy his house. Edward is receiving some assistance which has only happened recently. My mother's statement can provide further information in relation to this.

Section 8: Other Issues

58. I would like to see accountability for what has happened. Who knew that these infections were a possibility and authorised the medication anyway and

effectively ruined lots of lives? I imagine the doctors involved at least have had to suffer knowing what they have done and that must be traumatic for them.

59. I do not think that the Government saying "*sorry*" is good enough. It needs to be much more than that. I do not know what recompense should look like. Although I have suffered, it is for those who have suffered immeasurably more than I have to say what that apology should look like.

60. There should be recognition of the people who have died. Many more people have died since the Inquiry started. As a family we have been fortunate, however, there are many families who have not been. There needs to be some sort of acknowledgement that the deceased mattered then and still do.

61. I am happy for my evidence to be public and I am willing to provide oral evidence should I be required to do so.

Statement of Truth

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

Signed: **GRO-C**

Rosemary Elisabeth Buggins-Allsop

Dated: 7th January 2022