Witness Name: Rupert Miller
Statement No: W7234001
Exhibits:0
Dated: November 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF RUPERT HARRY MILLER

I, Rupert Harry Miller will say as follows:-

Section 1. Introduction

1. My name is Rupert Harry Miller. I reside at GRO-C GRO-C Poland. My date of birth is GRO-C 1958. I live in Poland with my wife and our son who is now 26 lives in Manchester. My wife is GRO-C and we moved to Poland in November 2020.

2. This witness statement has been prepared without the benefit of access to my brother, Julian Miller's full/medical records.

Section 2. How Affected

3. Julian was infected by receiving contaminated Factor VIII blood products as treatment for his Haemophilia.

4. Julian had Haemophilia A, and he had it very severely. We had to be extremely careful with Julian. When he was very small bruises started to appear on his body when he was a baby. The GP came round, he was a doddering old GP with no idea about anything. He immediately suspected my

parents of hitting him and wanted to report my parents for it. Fortunately, we had a nanny looking after us and she was very clued up and she said no, she thinks it was something like haemophilia and then he was tested, and the diagnosis confirmed. We had no history at all of haemophilia in our family, it can lie dormant in the female line for decades, for generations and suddenly appears. Julian was 2 or 3 months old when he was diagnosed, so very young.

5. Originally Julian was treated with cryoprecipitate whenever he had a bleed. My parents, usually my mother, would take him to Pendlebury children's hospital in Manchester where he would have the blood transfusion of cryoprecipitate, it was from a single donation, so it was clean blood. The problem with that however was he had to stay in hospital for around a week and my mother would then have to live in the hospital with him. My father was running his business and then you had my older brother and I who were then at home being looked after by our nanny. So, then our mother would be with Julian, he would have his transfusion and would then come home with his legs in plastic splints from his ankle to groin, with a joint at the knee. He was constantly in and out of hospital on a sort of revolving door basis for years and years until they came up with the magical Factor VIII home treatment.

6. When the Factor VIII came in, I think Julian would have been around 13 or 14 years old, he was a teenager anyway. He would have the stuff shipped by courier from the Oxford Haemophilia Centre, we lived in Cheshire. Julian would have his bottle of Factor VIII, his hypodermic needle syringe, and a bottle of distilled water. My mother used to inject Julian and I would on an odd occasion do it too. My mother found it incredibly upsetting to do which is why I would help; I was 4 years older than Julian. He then learnt, as he got older, to do it himself so would inject himself. The treatment then became prophylactic so he had it more often and it would work very well. If he felt like a bleed was coming on, he would treat himself. He would have bleeds for no reason at all, they would just appear. He had some monumental internal bleeding problems. Julian was pretty much reliant on a wheelchair from an early age, although he would walk with splints and sticks, when he had

bleeds, he would be pretty much reliant on his wheelchair. His legs would often be in plaster for months on end when he was young due to bad bleeds. He spent a lot of time at the Orthopaedic Centre at the Nuffield in Oxford, some of the bleeds were horrific, he would have massive bruising all over his body and would be in constant pain, but he would put a brave face on.

7. Julian would attend the Oxford Haemophilia Centre, which was his port of call, it was useful as he went to school in Oxford, he attended prep school, Dragon School in Oxford, just around the corner from Headington. At the haemophilia centre he was looked after by Dr Matthews and Dr Rizza.

8. Julian was infected with HIV as a result of the infected Factor VIII he was given. I do not believe he was infected with any other infections. I do not recall seeing Hepatitis being written in any of his notes.

9. Julian was told he had been infected with HIV in 1984, he was told he had the virus but at that time he did not know whether it would manifest itself into full blown AIDS or not. It meant that Julian was sitting on a time bomb, as we all were and each time Julian had a slight cough or didn't feel well, he would automatically think he was developing full blown AIDS. It put an incredible strain on Julian mentally and indeed all of us, my parents and in particular, my father. My father was incredibly affected by the whole thing, my mother was much stronger, but my father was deeply affected as we were all living with them. I had moved back as I lost my job because I was spending a lot of time helping to look after Julian.

10. In September 1990, I will never forget it, it was a Monday, 6 years of living on top of a time bomb, Julian woke up one Monday morning and had a temperature off the scale and could not breath. He was rushed to Liverpool hospital and that was the start, he had developed double pneumonia and full-blown AIDS, we then knew it was all over at that point, it was just a question of when.

11. Julian was born in 1962 so when he was told, in 1984, he had the virus he was 22 years old. Even though he had been told he had the virus and that he had got it from the Factor VIII he still had to continue to take the treatment as he was a severe haemophiliac so there was no question of him not, if he didn't continue to take the clotting factors, he would be dead anyway, he would bleed to death internally.

12. At the time Julian was told about his infection, he had at that stage been self injecting for probably 4 to 5 years, I am not sure what information he was provided with when he was told about it, but he didn't really have an option because of the severity of his haemophilia. Julian was aware of the risks of passing on the infection. I remember he struck up a friendship with a girl and she went to her GP for advice. She told her GP she was thinking of sleeping with a haemophiliac who was HIV+ and the GP told her not to do it, after that the relationship never took off.

Section 3. Other Infections

13. I don't believe Julian was infected with any other infection apart from HIV, but I could not be 100% sure.

Section 4. Consent

14. I do not know what information was provided about any risks relating to the use of Factor VIII when this was first prescribed for Julian.

15. When he was told of his HIV infection, Julian was at an age where he could make his own decisions and make his own mind up, I am not sure whether the doctors gave him only the bare information and not all they knew to protect themselves, all he was told was he had HIV and it could develop into full blown AIDS and that was tough. The doctors were working to help haemophiliacs lead a normal life, it must have been devastating for the doctors treating them when this happened. I know lots of people blame the

doctors, but really the blame lies higher up with the systems and the government.

16. Julian was aware he was being tested for HIV; he was constantly being tested.

Section 5. Impact of the Infection

17. The first thing was when Julian had double pneumonia, this was when he first developed full blown AIDS, he woke up with the high temperature on the Monday and went to Liverpool Hospital and he very nearly died there that first night. I was with him at the time, I had stayed with friends over night in Liverpool. I got up the next morning and went to the hospital fearing the worst, but he didn't die then, he survived that first night and when I got there in the morning, he was lying in bed very ill. I sat with him the night before until midnight just holding his hand, I had asked one of the nurses, Debbie, what was going to happen, she said he was very sick and it was 50/50, but he didn't die then, he was put under the wing of Dr Charlie Hay, a specialist AIDS doctor.

18. Julian then suffered from all sorts of things. His immune system was being eroded away. He wouldn't eat, eating and drinking became a problem for him, he lost a ton of weight, and his body was just closing down. My parents used to go up to the hospital with picnics for him, my father loved cooking and he would spend hours trying to invent and cook things Julian would enjoy eating, although with very little success as Julian would eat and immediately be sick. When he died a year and a half later, he weighed about 4 stone.

19. The impact of the infection also caused Julian to suffer with his mental health. He knew he was going to die; it was just a question of when. There are all these people alive today with HIV, but back then there was no medication that could stop it, all you could do was hope and pray he would recovery from each individual attack his body was under. What didn't help was that he was still a severe haemophiliac and still had all of those problems, the bleeding,

haemorrhaging took a massive toll on his body. His mental health was in turmoil.

20. Julian did a lot of campaigning and did interviews that appeared in the press, he took part in tv programmes and did a photo shoot with David Bailey. He took part in the Week in Week Out documentary and did an interview on Good Health with Dr Hilary Jones, all of this he did while he had HIV but prior to being hit with full blown AIDS in 1990. He did a lot of campaigning and was instrumental in getting the first 10 million from the government and the setting up of the McFarlane Trust.

21. He threw himself at the campaign. He did have a job as an executive in an advertising agency McCann Ericson in Birmingham, but that did not last long because he couldn't meet deadlines as he was at times physically unable to go to meetings, they did bend over backwards to help, they were brilliant, but at the end of the day they were a business, Julian realised and so he left a lovely job he adored and relied on benefits.

22. It really destroyed Julian mentally that he could not work and I think the biggest thing for everyone, my parents and myself as well as Julian, that there he was 22 years old and had just about got to grips with dealing with how to be a severe haemophiliac and then this happens, we couldn't believe it, it was incredible, no one could believe it was happening, we just couldn't understand how this could have possibly happened when you have the Government whose entire job is to protect its citizens. They tell you one thing and poison you with another. We really just couldn't understand how it was possible.

23. Julian had just met a girl, but he couldn't stay with her because of this problem, the whole thing just spiralled into a total and utter nightmare for him and everyone who loved him, it still affects me today. Julian was distraught. His death was not a good death. He was in a lot of pain controlled by morphine.

24. The infection destroyed Julian's private, family, and social life. When Julian could no longer work, he went to live with our parents in North Wales and so

there he was, in North Wales in a farmhouse in the middle of nowhere living with his mum and dad when all of his mates were living in big cities having parties, going out, having relationships, and working in good jobs, so you can imagine how that made him feel. He was isolated although he did have friends that would come and see him, but it was not the same.

25. Fortunately for Julian he did not experience stigma associated with his HIV infection. Julian's friends were educated and intelligent, so they understood the situation. Although a lot of the public felt that if you got AIDS, you were evil because you were probably a homosexual, a prostitute, a drug addict, or a criminal. That was all down to education and not understanding. The human race is a funny thing, if they don't understand something it is bad or evil and has to be destroyed, through ignorance. There was no real stigma in the community. I went back to live at home to help.

26. My mother was very strong on the outside but inside it was tearing her apart and if you know any woman who has given birth to a disabled child, they blame themselves. GRO-C GRO-C GRO-C My mum blamed herself all her life. My father was in pieces, and he loved cooking so he took solace in eating and drinking and couldn't cope with any of it, he fell to pieces completely. I was there helping to look after them and Julian, but it got to a point where it seemed Julian was getting better and for financial reasons I had to go and get a job.

27. I took a job in Manchester, but it all fell to pieces when Julian became ill again as I was spending time looking after Julian and neglected the job. They were awful about it, they basically said they didn't care my brother was ill, I was fired. It was not their problem, so I was out of a job again.

28. In terms of the impact on my family, without a doubt it killed my father. He just simply couldn't cope, and he died of a massive heart attack in a car in Poland in 1996, 5 years after Julian died. He was just a shadow of his former self. My mum was much stronger, much, much stronger, but when she was diagnosed with cancer, she decided not to fight it, she couldn't. You are

supposed to die before your children, but when you don't, there was the trauma and tragedy of my parents spending their entire life looking after Julian, being a severe haemophiliac he was a real challenge for them, but they adored him and then all of this happened. If he had been killed in a car crash it would have been different, but what happened was completely avoidable. Julian should still be alive today and my parents should still be alive, dad would be 100 and mum would be 90, lots of people now live to those ages.

29. In terms of how it affected me, I ended up marrying a woman I should never have married but needed a crutch while it was all going on. When Julian died the marriage fell apart quickly. I drunk copious amounts of alcohol, I had suicidal thoughts. I had a job in London which went bankrupt on me and then by pure chance I bumped into an old friend, Anton, who I had not seen for many years. Anton gave me the opportunity to work with him in Poland in 1993. After my marriage collapsed, for lots of reasons, I was not thinking straight and was drinking heavily, I bumped unto Anton and he gave me the opportunity to run away, which I did, I went to Poland. I didn't speak to my parents for years, I haven't spoken to my brother for 20 years, anything to do with reminding me of Julian I shut out, closed off completely. To help I started writing about it as early as 1993. I was not going to kill myself, I had finally got over that idea, but there was all these thoughts. I thought about it, I considered it, but there is then the guilt, my parents had lost one son and now they had lost another and I still have that guilt with me today and wonder whether this contributed to my father's death or not, I did not speak to him for 3 years, he was trying to find me in Poland. In those days there were no phones and no internet. Poland then was like the wild west; it was the end of the cold war. The place was full of factions fighting for power, it was just a nightmare, although I met Kasia, who saved me. We have been together for 30 years now.

30. I am a great believer in fate, although what has happened in the last 5 years or so while campaigning and the Inquiry has re-opened all the old wounds again. I was pretty ill after it happened. He was my brother, my best friend,

we did everything together and as I have said before if he had been killed in a car crash that is one thing, he was murdered, it should simply not have happened, the government is to blame.

31. In terms of Julian's education, this was impacted enormously. Our parents were well off and well educated, Julian and I went to Dragon School in Oxford, a top private prep school for boys aged 8-13 and the Orthopaedic Centre for Haemophilia was in Oxford, so he was looked after very well there and also the school in Oxford understood the problems Julian had and were brilliant, they bent over backwards to help Julian in lessons, he would have lessons in bed if he was unable to get to the classroom. They were really professional educators, they were fantastic. We went on to Harrow after that school, but when Julian followed there they had no understanding, they were useless and my father went ballistic, when I left in 1976 Julian left as well after being there only 2 years. My father wrote stinking letters about their behaviour. They were useless, it was a great shame so in 1976 he went home to my parents.

32. After Harrow, Julian went to a local comprehensive school in Cheshire, he would have been around 14 at the time. He also had home tutors. At this point he was suffering with his haemophilia quite badly as he was growing fast, he had a growth spurt that caused huge problems with his knees and as a result he spent a lot of time in hospital and missed a lot of schooling, although that said, he was bright and ended up with 'O' Levels and did his 'A' Levels at Winsford and then went to Birmingham University. He was very fortunate, at university he met John Seagrim who became his closest friend and who looked after him completely, it was like he had his own personal valet, they lived together in Birmingham when at University and John looked after Julian all the time. By this time Julian had stopped growing, so the episodes of bleeding had gone back to normal, he was on home treatment, so this is when he started to lead some sort of normal life albeit with the restriction's haemophilia imposed upon him.

33. It was very fortunate our parents had the means to support Julian, he had a mobility car he could drive as it was automatic, my parents looked after him when he was at home and John Seagrim was the saviour in Birmingham. I

was up in Birmingham for work a lot so I would pop in and see him a lot as well.

Section 6. Treatment/care/support

34. I am not aware of Julian experiencing any difficulties or obstacles in obtaining treatment care or support as a consequence of being infected with HIV.

35. I think counselling was discussed, but you know this was all pre mental health begin discussed openly, it was brought up, but we had the "*there is nothing wrong with me*" stiff upper lip mentality. That is what I was like when I was going through turmoil, I didn't know I was doing through turmoil until I reflected on it, it was all gung hoe, carry on, that kind of attitude, that's how we were brought up in those days. If you were a man, to show signs of needing help, that was viewed as weakness back then, for a man to cry was unheard of back then, it was very much frowned upon, psychiatric support, well that was for nutters, not for me, so "*no thank you very much*" was how I viewed it. Julian being disabled, the biggest thing about being disabled in his entire life was his independency, his ability to do things on his own without help, thank you very much. He needed help, lots of it, but didn't want to admit it, but I think counselling was discussed but never happened for those reasons.

36. I did have private counselling which was arranged for me by my ex-wife. However, it did not last as I was not interested as I felt it showed "weakness". I did also breakdown in public on several occasions.

Section 7. Financial Assistance

37. Julian received payments from the McFarlane Trust and also had interim payments for things like holidays other than the usual bureaucratic form filling he had no problems with it, dad dealt with it for him. He received a small weekly payment of £20 in February 1988. He received a payment of £20,000 in 1990, £23,500 in 1991 and smaller payments as contributions towards holidays, my father received a contribution towards Julian's funeral.

Section 8. Other Information

38. It has been essential to keep the campaign in the press as much as possible, to follow on from the campaigning Julian did when he was alive. Over the years I have tried to get the Sunday Times involved via one of their reporters, but he hinted to me, without saying it directly, that Julian and I were too posh for today's hard luck stories, but it can affect anyone.

Anonymity

39. I do not wish to remain anonymous.

40. I do want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-C ..

Dated 21 / 11 / 2022