Witness Name: Matthew Parsons
Statement No. WITN5367001
Exhibits: Nil
Dated: 18.4.22.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MATTHEW PARSONS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 November 2020.

I, Matthew Parsons, will say as follows: -

Section 1. Introduction

1. My name is Matthew Parsons and I was born on GRO-C 1977. I live at an address known to the Inquiry. I am an accountant by trade and I currently work for an insurance company. I have worked with them on and off for 14 years. I qualified as an accountant in practice. I am married with two children, twins who turned 13 before Christmas.

2. I intend to speak about my infection with HIV AND hepatitis C ("HCV"), in particular, the nature of my illness, how the illnesses affected me, the treatment received and the impact they had on myself and my family, and our lives together.

3. I can confirm that I am not legally represented and that I am aware of the provisions for anonymity and I am happy for my story to be in the

public domain.

4. I have Haemophilia A. I was diagnosed with Haemophilia when I was six or seven months old. It was suspected that I would have Haemophilia because my mother was a carrier. She is from Burma and has experience of the condition, having lost both her brothers due to bleeding issues. She knew about Haemophilia and was aware of the possibility of having a haemophiliac son. I am now on prophylactic treatment and I have moved over the course of the years through many different treatment regimes.

5. My deficiency is in Factor VIII. I have less than 1% and any bleed requires treatment. My first bleed was on Christmas Eve back in 1977. My mum accidentally shut my foot in a car door and I went to hospital and had treatment. I am not sure where on that occasion but my main treatment over the years has been provided by the Royal Free Hospital, Katherine Dormandy Unit. I do not remember the name of the products I had as a child.

6. The majority of my regular care was dealt with by the doctors at the Royal Free Hospital, although I often was treated at Hillingdon Hospital as I have lived in and around it's catchment area most of my life. If I had a bleed, up until I was about 7 or 8 years old, I would go to hospital for treatment. I would go either to Hillingdon or the Royal Free Hospital. After that, I then went onto home treatment. Initially my mum would apply the treatment until I learnt how to administer it to myself when I was about 12/13.

Section 2. How Infected

7. I am not sure of the exact date of when I was diagnosed with HIV. I was diagnosed well before I knew about it. My parents knew about it first. I remember having a discussion with a doctor when I was very young and

didn't really understand what was being said. I was off school for a period of time and I knew I had something wrong with me but what that was it.

8. My mum and dad withheld the notion of Hepatitis C and HIV from me. When I was 15, probably around January 1992, I was going more and more regularly to the hospital for tests. It was getting to me and I was quite upset about this and told my mum. It was at this stage that she told me I was HIV positive. She explained my blood levels had reached a point that meant that I now required treatment. It was difficult to take in and I was shocked but truth be known I didn't really know how I felt. But at least, off the back of that, I then understood what was going on with my HIV status.

9. After that, I then went back and had discussions with the doctor as to how to understand the infection and it was at that point, I started to learn how to manage it. I saw Dr Goldman at the Royal Free. When I was told I had HIV it was explained to me that it was likely it would go on to become AIDS. It was really upsetting at that time and very hard for a 15-year-old lad to come to terms with. Other doctors were involved from time to time but Dr Goldman was responsible for the majority of my care.

10. In the late 1980's and early 1990's it was so different to today, you were constantly seeing the advertising around HIV and how bad it was. It was everywhere – and nothing was positive. You then started to worry about everything you are doing and what might be happening. I have a younger sister – I was constantly worrying about my needles, where they were after using treatment, ensuring that nothing was left lying around. I am sure my parents must have had the same concerns although they never said.

11. I was 15 and I was going into my GCSEs. There was a period of time where I just thought; what am I doing? Why am I carrying on? My mood

was low and on occasions I thought is it worth it? I am not quite sure why, but I got through it. It is probably the way that I decided to deal with it. I developed a strategy whereby I only started to think about these things around the dates of hospital appointments. That way I blocked out the possible consequences of my infections at all other times. Outside of this window, I tend not think about it. Whether or not that is a good thing, it is how I deal with it.

12. Hepatitis C was something that was discussed with me around that same time. I was 15 or 16 when I found out. I can't recall at what point it was discussed, I don't think it would have been at the same time as the HIV revelation but possibly a short time after. But I can recall it becoming more of a focus. As I got older and went to university, my treatments were changing. I was starting to take treatments for both Hepatitis C and HIV.

13. When I ended up with the diagnosis for Hepatitis C on top of HIV diagnosis, I felt worried but it didn't mean that much. My main concern as always was about whether you can pass it on. It was another worry that my family may be at risk. Later, it played a big part in the relationship I had with my wife. How do you ensure that she is safe? The concern is ongoing.

14. When I was told about the HCV, it was less of an issue. It did not feel like it was anything that was going to kill me. I had blood tests and checks on my liver. There wasn't any serious deterioration of my liver at that time. It was as I got towards the end of the 1990's, into the early 2000's, doctors started to talk more about Hepatitis C. I don't recall any specific precautions or advice being given to me at the time but it may have been provided to my mum and dad.

15. I was offered treatment and managed to clear the HCV. I don't believe I ever had a biopsy. I did have liver scans. I don't believe there was

anything in terms of a specific biopsy or any detrimental findings in respect of my liver.

16. I should add that I have never had a blood transfusion, never been an intravenous drug user, have no tattoos or piercings, and am happily married. I have had a treatment overseas in the US at a hospital for a bleed in relation to my haemophilia but used Factor VIII that was brought with me on holiday to the USA.

Section 3. Consent

17. I am not aware of having given consent for treatment in my youth but I am sure my parents gave it at the time when I was using blood products. They have never discussed this aspect with me. I am not aware as to whether they knew specifically that my blood was being tested for HIV or for HCV. However, It is likely with HIV as it was such a concern at the time.

18. I am certainly not aware of any warnings being provided about any risk being attached to the use of blood products. I believe if such risks had been outlined to my parents, they would have mentioned that fact to me a later stage.

Section 4. Treatment and Support

19. In terms of treatment, I started on AZT for the HIV. I also had to take some other medication related to the impact of the drug on my system. I was taking Thalidomide and another drug called 3TC for a period of time. This treatment kept me stable for a period. Over the years I have gone through multiple different variations in viral treatments to get to the

right one for me.

20. I have been on this latest combination treatment now for 10 or 12 years. My viral load has been under control and remains undetectable. My CD count has not climbed significantly but my HIV status has remained at a manageable level.

21. In terms of monitoring, I think I went into the Haemophilia centre every three months and in a way the frequency has almost stayed the same. Now I have twice yearly appointments for my Haemophilia and twice-yearly appointments for my HIV.

22. It was Dr Goldman treating me until I was about 18 or 19 for my Haemophilia. It went out to a few different consultants on occasions as mentioned. My treatment was transferred over to Professor Margaret Johnson. I believe I did see someone in relation to the HCV for a short period but I can't recall any names.

23. I was offered psychological support in the early days at the Royal Free Hospital, off the back of my reviews for haemophilia. I saw one of the family therapists at that point. For most of my time, my doctor was doctor Goldman. She had a therapist whom I spoke with afterwards.

24. She talked to me about my haemophilia up until I knew about my HIV, then we progressed onto that. I don't recall any specific referral when I was told about the HCV but I am sure we discussed this as well. When my wife, Siobhain became more involved, we saw her together. It was useful to be able to talk things through and possibly more of that type of assistance should be available to those who want it.

25. I do have to say that I did get to a point where I did not enjoy talking to someone about it. Initially it's good to get your feelings off your chest and as I've said if you want help it should be there but optional –

especially frequency.

26. My particular focus has been to box it all off into that day of treatment. I am still an absolute arse the day before I go to hospital and the day after but then I don't think about it.

Section 5. Impact

Personal Life

27. I met my wife when we were still at school. I had to tell her of my status at some point. It was quite agonising to go through and think about at the time, planning the right moment and exactly what to say. Wondering; how will she react? I guess the main focus has always been to make sure that she was always safe from possible infection. That was always my maxim with family. She probably hasn't had the same sort of support other that the therapist that I mentioned, although that is limited. She has come to the centre with me from time to time - not on a regular basis and not recently. It all had a big impact on where we were at. It was stressful for both of us.

28. The biggest issue as you go through the treatment and you find it hitting you is, when you get to the end of it you wonder 'what if it hasn't worked?'. I am very lucky on that basis that I did not have go through it again. The biggest impact for us was around having kids. It took us a while to get the treatment that we needed. To get the right referral.

29. I cleared the Hepatitis C, we got married in 2003, and did not have kids until 2008. The main impact for us was the time delay in being able to start a family. I was referred by Royal Free to different hospitals, including UCH and Chelsea and Westminster but things just seemed to get lost in processes. Time passed and we were not eligible for funding so went down the private route and paid £3000 for a sperm washing

procedure and resultant IVF.

30. My children and family are not aware of my current status, not yet. My HIV status remains very private. I do not discuss it with my friends. It is something that I have just kept to myself. Whilst you would think that the stigma has gone away, you do not know for sure. There is still prejudice - and ignorance of the condition. I try to be exceptionally careful. I do not believe that it would be a huge issue but I have decided that it is better not to make it any issue.

Treatment

31. I was on AZT as a main medication for a while, then it was paired with 3TC and then eventually I stopped the AZT. I remember I had to have a fridge which I kept in my room at university for one treatment regime in the late 1990s. It was just to try and avoid anyone else seeing my treatments. I also recall trying not to drink so much because it may damage my liver so I must have been given that advice at some point.

32. I went on treatment in 2001 or 2002 for Hepatitis C and managed to clear it. It cleared it on the first cycle but the side effects were horrific. I had an Interferon injection once a week and took ribavirin tablets daily. I am used to injecting myself quite regularly into veins but after a period of time I could not do the injection into my stomach with the Interferon so I had to get my wife to do it for me.

33. One treatment also caused internal bleeding in my kidneys. At that point it was a new side effect. I took the treatment at the centre, came home, and had back pain. It could have been a tablet called Indinavir used as an inhibitor for my HIV, whilst they tried to find the right combination for me.

34. With Interferon, the main side effects were mood swings and a feeling of being very low and depressed. I felt very lethargic, not wanting to do

anything. Having that treatment at the end of a week and going back to work on a Monday - it was wearing on me. I just wanted to sleep. I can't imagine what it was like for my wife Siobhain. With the being 'down' and tiredness I was probably a right pain.

35. I was also getting rashes around where I had the treatment and I did not feel right for a time, feeling heavy and foggy. I was not able to do everything I wanted to do at a normal capacity. I was lethargic and slow.

36. My initial HIV treatment had also caused problems, things like ulcerations in my mouth, which would cause difficulty in eating. That was combined with other treatments to try and resolve those issues.

37. My elbows are very bad, they seem to be the target joints from my haemophilia. Essentially haemophilia caused arthritis in my elbows. Hepatitis C I believe, also had an impact. I can remember the risk being mentioned as I got older, as it was something that started to come more into focus later as treatment was discussed. I am aware that there is a correlation between HCV and joint problems and that it may exacerbate these.

38. It is possible that I was subject to experimental treatment, as a trial. I was aware of the changes I was provided and there was a need to see what drugs worked best together and provided the most resistance to and relief from the symptoms of the infection.

Family

39. My mum in particular is constantly worried about my health. It had a huge impact on her. The fact that I was a haemophiliac and she lost her two brothers to it did not help but it has had a big impact on both my parents. They probably worry about it more than I do. My mum certainly does. It has accounted to for so much of their lives and they had to invest so much time and energy into my care in the early days. They

were so used to seeing a doctor to tell them whether or not I was doing ok. And now they rely on me to tell them the truth.

40. I can't imagine how they felt for six or seven years of going through that without me knowing and trying to hope that they would get to a point where there would be a treatment available for the HIV. At that point there was no treatment available. It was effectively a death sentence. I can't imagine how horrific that must have been for them.

41. Again, it was kept from my sister for a period of time until she was old enough to know about it. She now understands more.

<u>Work and education</u>

42. Fortunately, there was not a huge impact on my education. I was excluded from my primary school for a period due to contracting hepatitis but I had a teacher who came and taught me at home.

43. I did miss regular amounts of time because of health treatments. In my second year of university, I started to get lots of ulcerations in my mouth and in my throat – I could not get rid of them. For about four or five months, just eating was very difficult, which meant missing classes and not being able to do as much as I wanted. It had an impact on my second-year examinations, although I caught back some of the marks lost in my final year.

44. With my employers, they still do not know about my HIV/HCV status. Every employer has been aware of my haemophilia. I take annual leave to go to appointments because they are so regular. With the Hepatitis C treatment, I am not sure how I managed to do both at the same time. I often felt so under the weather and terribly fatigued but somehow, I got through it. Maybe some of them noticed but there was never any comment about my work being affected. I was a trainee accountant at that point. I had just finished my exams thankfully but I was just

managing work to try and minimise the amount of time I had off.

Life Plans

45. The infection has inhibited my life in a certain way because I have not gone and done many things that I might have wanted to do. I would have travelled more and I would more than likely have gone on to work and live overseas, particularly in the USA where my employer provides many opportunities to work.

46. I do believe that I would have progressed further within my chosen field without the twin infections. I take the safe option now due to the fact that I am always worried about the treatment and having access and any change in how it affects me.

47. My attitude to getting older changes over time. After the initial diagnosis, I did not think that I had very long to live. When I was 15 and my count was dropping, the likelihood would have been that I would have regressed quite quickly even with the treatments I was on.

48. Within a few years with the advent of retrovirals you begin to think 'ok, this is something I can live with'. My assumption is that it is going to be limiting on my life span. I still have that belief and want to make every day count. The assumption is, I have HIV and I am going to die.

49. I felt a great relief when I was cleared of Hepatitis C. It is just one thing that I did not have to worry about any longer. My wife had to have the tests before having kids as part of the process. She had to be tested to show that she was negative to demonstrate that the process hadn't caused an infection. That was a nerve-racking period for her with the wait for the all-clear.

50. The advice I have had is that whilst my viral load is undetectable, I am not infectious, while under treatment. We have relied on that. In terms of

sex, we have always used contraceptives, even now. It is not worth the risk and I certainly would not take it.

Section 6. Other Infections & General Health

51. I do not remember receiving a specific letter about vCJD. I may have received letters saying there was no risk.

52. In fact, I assumed I probably had it. Given how blood was treated, if there was a risk, it was probably there. I remember having discussions a long time ago about vCJD. At the time I was quite anxious. There is no treatment for it. There is no way of knowing whether you have it until you do have it.

53. Back then it was concerning but over time I have thought about it less and less. If it happens, it will happen at some point in the future, having been passed on through the treatments I had. There is nothing I can do about it. It is just another part that demonstrates the negligence of those involved in sourcing and providing blood and blood products during that period.

54. I have an issue at the moment. I am not sure what has happened, but I am seeing someone about it. I have had some issues for the past six months with what I thought was a bad back which has evolved into a weakness in my legs, my right leg, muscle cramping, constant tremors and muscle facilitations. I spoke to the doctors at the haemophilia centre. They did some initial tests and said it was dehydration. In the summer I started to get a lot weaker. Then I went back to the GP. The GP sent me to a physio. This made no difference so I got a referral to a neurologist and last week had some tests to examine motor and neural functions. I do not know whether it is a side effect or something else.

55. Regarding the above, there is an update as of February 2022. I am seeing a Neuro-specialist at Wexham Park Hospital in Slough and have been admitted for tests to the National Hospital for Neurology and Neurosurgery in London. Based on the results, I have developed a Motor Neurone Disease that is slowly progressing and affecting my lower body. The symptoms are similar to an MND like illness which afflicts many of those patients diagnosed as HIV positive and is considered to be linked to either HIV itself or the medication used to treat it. I have further appointments at the National Hospital for Neurology and Neurosurgery in London to understand the longer-term implications of the MND diagnosis.

Section 7. Financial Support

56. I am fortunate in that it hasn't had a significant impact financially. When we first applied for a mortgage, there was a bit of a worry about what might happen but we were able to get one. I was never able to get life insurance. We have been very fortunate also in that I am in a good position work-wise albeit I do feel, as I've said, that I could have moved further up the ladder – with the additional financial benefits that entails, without all the problems attributed to my infections.

57. Travel insurance has been a problem although I have been able to get it through specialist providers but always at a premium cost. It has got better as of late.

58. It has caused losses from a financial perspective over the years with continuous travel to and from hospital for my mum and dad and possibly, loss of earnings with time off but I have no idea of the figures. I myself have been able to work around many of my appointments or use

time off or leave when necessary.

59. My application to the Skipton Fund for funding was successful. My parents made the application on my behalf. They applied in December 2004 and this was paid out in May 2005 receiving a first stage payment of £20,000. The application itself was in the name of Mr and Mrs P. Parsons. I believe that we received the information on the Fund from the Haemophilia Centre.

60. I currently receive monthly payments from the English infected blood support scheme. I get £3200 per month and then I received a top up payment that was made just before Christmas. These are combined payments in respect of both HIV and Hepatitis C.

61. The money from Skipton was put in an account for me. Myself and my wife used it for our deposit.

62. I have received payments from the Macfarlane Trust for HIV and again some of it went into an account for my later use.

Section 8. Other Issues

63. Historically, to enter the USA, which I need to do for business reasons, you need a visa to go in with HIV. I have an issue whereby wherever I go in through customs I get stopped. There is a question as to why that is happening.

64. In terms of government competence in managing things, absolutely. The way that they acted and continue to act taints different things and different people. The attitudes of people who come in front of the Inquiry makes me quite angry. Certain ex-ministers allowed this to happen and have conducted themselves through this Inquiry in a way that shows

little sympathy or empathy for the impact on patients of the decisions they made. It is very unfortunate. In terms of my care within the NHS, I have no reason to think that people did not act in my best interests.

65. My hope for the inquiry is that the process identifies why the decisions were made to put people at such a risk, explains why these decisions were taken and provides ongoing support to those that have been severely affected. Whatever the outcome, I would want it to ensure that the Inquiry identifies controls to ensure something like this does not happen again. I have lived with HIV for the best part of 30 years. Given the timing of when I was infected, I was fortunate to get to 15 and then be able to receive treatments such as AZT which prolonged my health until better treatment regimens were available. I often think about the hundreds of people who weren't as lucky. I hope that the whole process gives those infected and their families some support.

Statement of Truth

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

Signed GRO-C

Dated 18 APRIL 2022