Witness Name: Jonny EVANS

Statement No. WITN0362001

Exhibits: Nil

Dated: 11th / March 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

JONNY EVANS

I provide this statement in response to a request under Rule 9 of The Inquiry Rules 2006, dated 6th December 2018.

I, Jonny Evans, will say as follows:-

Section 1 - Introduction

1. My full name is Jonny Evans and I was born in GRO-C Wales on GRO-C 1959. At the time of my making this statement I am 62 years of age. I am a married man, having been married for some 41 years to date, and am now retired as is my wife, Ann.

2. In spite of our having both now retired, we still own a smallholding, but the farm is let to another farmer for sheep grazing and I no longer undertake what can best be described as having been physical labour. My wife and I live at an address in Wales which is known to the Infected Blood Inquiry.

3. I was my parents first born child and they then had a daughter, my sister, in 1962. Sadly, we lost her as a result of a brain tumour in 2008.

4. Within this statement I intend to speak of my infection with the Human Immunodeficiency Virus (more commonly known as HIV) and Hepatitis C (also known as Hep' C and / or HcV) which was the direct result of my having been treated with contaminated blood and / or contaminated blood products for haemophilia. I will detail how I came to be infected, the nature of these ailments in so far as they have impacted upon me, the treatment I have received, and the impact such illnesses and their treatment has had on my life and that of my wife, family and friends.

Section 2 - How Infected

5. Although it was unknown to us at the time, I had been born with haemophilia, a condition which hadn't been identified at or prior to my birth, but with no known familial history there had been no cause for any such ailment to have been looked for.

6. As a crawling baby and then as a toddler, as is usual with young children, I bumped into things and fell or tripped, but unlike other young children, I noticeably bruised a lot. This is not a situation that is unusual with haemophilia, but as it had not been diagnosed at that time, my parents were looked down upon by others and my mother in particular regarded as someone who'd been mistreating her child.

7. Fortunately, our family General Practitioner (G.P.) was very good and very supportive of my parents and I, and at around two and a half to three years of age following repeated incidents of my bruising, arranged for my blood to be tested. The result came as a complete surprise to all concerned, in particular as there was absolutely no familial history, but I was found to have haemophilia with a 0% clotting factor – Severe Haemophilia or Haemophilia 'A.'

8. This would have been in around 1961-1962, when there was apparently no known treatment for haemophilia. My parents were merely advised to be careful and to keep an eye on me.

9. When I as about five or six years old my parents bought me a pedal car. One day, when I was riding in the car in the street outside of our home, a neighbour seeing me came out and gave me a push. The car turned over resulting in my becoming trapped under it, in particular one of my legs which sustained a lot of damage as a result. I was hospitalised and ended up having to wear a calliper (a form of metallic leg brace) on the injured leg for several months.

10. My mother told me that one day, whilst wearing the calliper, a passing old lady made what I imagine she believed to have been a sympathetic comment to my mother in which she referred to me as being a "poor little cripple." This really upset my mother who took such exception to it, and the way in which I was being regarded, that as soon as we got home she took the calliper off, threw it into the bin, and I didn't wear it again.

11. Aged around seven, my parents were deliberating upon my education with my mother having decided that I would be best placed in a mainstream school as opposed to any form of 'special school' for ill and / or disabled children. From the first diagnosis, she had always been reluctant to wrap me up in cotton wool, and believed that it would be better for me to learn to adapt and adjust to living with my condition in the real world rather than being shielded from it and struggle in later life.

12. I am immensely grateful to my mother for this decision, which must have been a hard one to take, but it was wise and enabled me to grow up doing or at the least being exposed to everything which the other children were able to experience, whatever the outcome for me may have been.

13. Having been diagnosed as having severe haemophilia, from approximately 1962 onwards I spent a lot of time being treated on the Children's Ward at the Morriston Hospital in Swansea, Wales. Back then, there was no dedicated haemophilia unit, so I was treated alongside other children like me or with other chronic health conditions, many of whom I became friendly with.

14. Frequent severe bruising led to a lot of time spent in hospital and as a result, a lot of school time being 'lost.' As a result, whilst an inpatient at Morriston, I was given a tutor to help me, but there wasn't a particularly comprehensive curriculum in the hospital. I basically engaged in self-education, by supplementing that which I was given through the tutor by a lot of independent reading at home – when confined, I couldn't do much, but I could read, so I did and it helped fill in some of the holes in my education.

15. As and when I suffered a bleed, the only means of it being addressed was for me to be taken into hospital as an inpatient, where I would be 'hooked up' to an intravenous drip of whole blood which I then received by transfusion as the clotting factor it contained would have been of some help. I do not know, as I was so young at the time, but I can only imagine from what I have been told and learned, that I had been given whole blood from a very early age and often spent several weeks inn hospital at a time.

16. The bruising and other uncontrollable bleeds aside, I would also suffer severe nose bleeds as a result of my haemophilia, a situation which persisted well into my early teens – the only remedy appeared to me to have been to have my nose 'packed' to staunch the flow of blood.

17. I can't tell if my mother having discarded the calliper had any long-term damaging physical effects. When I entered mainstream school, I was a very physically active pupil, playing various sports, which served to help strengthen and develop the muscles of my limbs, which helped with the joints and my overall physical development.

18. Although, due to my ailment, I didn't start mainstream schooling until I was seven years old, I believe that I was nevertheless reasonably academically capable and didn't have any problems in catching up with the other children when necessary, but all the same the curriculum then was effectively limited to reading, writing and arithmetic and as such wasn't overly challenging.

19. When it came time for my transition to secondary school, mother considered my being held back a year at junior school, as having been born in August, she had an option to do so, but I decided against this, passing my 11+ examination with ease, and entered mainstream secondary schooling.

20. As I approached my teenage years, I did not experience many incapacitating injuries, in spite of my sporting activities, and bleeding episodes became less frequent, albeit each one was now more severe. Whenever I experienced an injury, a bleed, I would be hospitalised for at least a couple of days each time.

21. My care as a child had remained at the Morriston Hospital until 1968 when I was nine years years old, and had always seen my being treated with whole blood as opposed to any form of blood product. My first treatment with Cryoprecipitate was in June 1968 and took place at the Cardiff Royal Infirmary where I was under the care of Doctor, later Professor Bloom who held a position covering all of the Cardiff hospitals.

22. Looking back, now many years ago, the only truly prominent memory I have of this time and my having been a Morriston inpatient was of the arrival of the phlebotomist onto the children's ward, memorable for his having entered carrying a large wooden briefcase filled with vials. I can remember both myself and the other children running off to hide, and referring to him as 'the vampire,' coming to take our blood!

23. Having passed my 11+ examination, I was able to go to the local grammar school, this I found to be a whole different world to what I had experienced at school before. I was treated pretty much the same in so far as my general care and welfare were concerned, but the school had never heard of haemophilia before and thought that I had some form of 'brittle bone' disease.

24. My mother had to have a discussion with the headmaster before my first term began, and asked that I be treated as any other boy would be, which he respected. My mother always trusted my judgement in so much as she understood that I knew when something was wrong with my health.

25. I cannot now recall any instances of my having been hospitalised for any injury resulting in a bleed requiring treatment due to any sport or playground activities – I used to play soccer and even dabbled with rugby. I always seemed to be the first choice as a goalkeeper as I was quite happy to dive for a ball, regardless of the nature of the ground or the weather, and having been brought up to 'get on with things, adjust and adapt,' did just that – haemophilia wasn't going to hold me back from doing anything. I was determined to live life as I wished, but outside of school there were lots of knocks and bumps which resulted in my needing treatment and consequently my missing a lot of school.

26. When I was about 11 or maybe twelve years old, sometime in 1970 and shortly after my having stated at the grammar school, I suffered an elbow injury. I had gone to bed with a mere bump, but awoke in agony with a significant swelling. An ambulance was called and rather than being taken to the Morriston Hospital, which had been my normal route for treatment, I was taken to the Cardiff Royal Infirmary - as referred to in my paragraph 21 above regarding my first treatment with Cryoprecipitate.

27. Here I was seen for the first time by Dr Arthur Bloom (later Professor Bloom), then a newly appointed haemophilia doctor. For the first time in my life, I was treated through my being given an infusion of cryoprecipitate (or 'cryo' as it is commonly referred to), a blood product. For me at that time, this was ground-breaking as there was an alternative to treatment with whole blood and resultant lengthy stays in hospital.

28. 'Cryo' is etched into my mind as having been a revolutionary treatment for haemophilia. Prior to the introduction of cryoprecipitate I had become accustomed to hours of pain following even a minor bleed and weeks of hospitalisation, However, within hours of my having been given cryo, I found that swellings diminished and the pain subsided, I would only have to remain in the Cardiff Royal Infirmary for a couple of days – with whole blood, even with the mildest of bleeds, I'd be in Morriston for at least a week.

29. Dr Bloom most probably explained to my mother the nature and purpose of cryoprecipitate treatment, but I can't imagine that I would have taken much, if any notice of any discussions concerning my treatment, I just wanted to know that I could be treated and would be getting out again, and as soon as that may have been possible, I was too young to be concerned with much else.

30. My mother harboured an old-fashioned faith in the medical system and NHS as a whole, and as such it wasn't in her nature to question things she held great trust in. My village G.P. was aware of the treatments I was receiving, but until I went to Cardiff, I hadn't met another haemophiliac, so I recall that he appeared to have taken a particular interest in my condition and its treatment, but there was never any support available for us as a family, no people to talk to who knew what we were experiencing, no psychological support and nothing financial.

31. From the time of my elbow injury onwards, and its treatment with cryoprecipitate, if ever I suffered a bleed I was seen by Dr Bloom in Cardiff which was developing into a dedicated regional haemophilia centre, but I can now only remember two occasions when my condition required this, the elbow injury and an occasion when I was given some cryoprecipitate prophylactically, about a year later, to facilitate some dentistry work I needed to have done (extractions) as I used to wake in the mornings with bruised gums and a mouthful of clotting.

32. Under the care of Dr Bloom, I began to self-administer Factor VIII, but with Cryopreciptitate there was no such possibility - it was always given in hospital and wasn't made available for use outside of the same.

33. I assume that I was seen on the Children's Ward at the Cardiff Royal Infirmary as whilst there was a haematology department, there wasn't a dedicated haemophilia ward at that point in time. Shortly afterwards, whilst a new hospital was being built, I had to be seen on two occasions at the University Hospital, Llandough (also in Cardiff) as an interim measure, but I cannot be sure if I was in a children's ward there or not as the other couple of boys being treated there were both much older than me.

34. The above occasions aside, every time I went for treatment or to attend a clinic for review, I went to Ward A7 of the University Hospital of Wales (Cardiff) to be seen by Dr Bloom, there was still no dedicated haemophilia centre. As I continued to be physically active in my teenage years, I occasionally suffered severe bleeds which meant that I was again hospitalised for a few weeks at a time. As a direct result of successive severe bleeds, I developed a weakness in my right leg.

35. I took up cycling, and in my early teenage years became somewhat fanatical about it, in part driven by the fact that not only could I do it, and found it good for my general health mobility, but that I was actually very good at it. I joined a local cycling club and would cycle for hours and often many hundreds of miles at a time. It was a non-contact activity I could undertake without having to worry about the consequences for my haemophilia, and it helped develop excellent cardiovascular fitness and strengthened my legs.

36. Cycling allowed me to believe that I was somehow rising above haemophilia, something I no longer considered to be a disability. At the same time, despite still being a schoolboy, I was working, undertaking hard manual labour for my father who was a plasterer.

37. At my junior school I had been able to take the education delivered in my stride, but at secondary school I struggled to keep up, although I did achieve five O' Levels and 2 A' Levels. I could have applied myself more at the grammar school, but missing schooling there was hard to address as I had been able to do previously, so my overall grades and qualifications were lower than they may have been, but I have no regrets or complaints to make about this and don't think that I'd have been in any better place than I am now had things been any different for me at school.

38. I have in more recent times sought access to my medical records from the Cardiff Royal Infirmary / University Hospital of Wales, and found that they had a very good technical officer working in the Haemophilia Centre there who really helped. In his own time, he searched for my records and found some which had been misfiled where, were it not for his assistance, they would never have been traced. All the same, many of the records seem to have been disposed of although I do have some copies of what remains, thanks to him.

39. In around 1974, when I would have been 14 or 15 years of age, following two or three years of using cryoprecipitate, my treatment was changed from cryo' to Factor VIII, an alternative blood product to cryoprecipitate which I could also store and use at home, self-administering. I was taught how to self-administer by the staff in Cardiff, but there was then still no haemophilia centre. We kept the Factor VIII we were issued in the fridge at home, but had to collect it from the hospital and I can remember my mother complaining that for us, Cardiff was a fifty mile trip, but no help was given with the travelling costs we incurred. I continued treatment with Cryoprecipitate as an inpatient until 1980 or 1981 although Factor VIII Concentrate had been made available for my home use from 1975.

40. I had a problem with home treatment in so much as I regarded myself as being 'super-fit' and active, in particular as regards my cycling pursuits, and was reluctant to self-administer unless absolutely necessary. So, quite often I wouldn't take it – four times out of five, something like that, but these were the correct judgement calls. I didn't take it 'willy-nilly' just because I could.

41. However, I didn't always get it right, and when I abstained from treatment, but had got it wrong as I'd actually experienced a severe bleed, it would lead to weeks of hospitalisation again and I now regret my rather arrogant approach to home treatment as a teenager. The clinical recommendation back than was more geared to treatment on demand, reacting to need rather than prophylaxis – to administer as a preventative measure, such as when you know that you may suffer a bleed.

42. Nowadays, I wouldn't hesitate to treat a bleed and in retrospect I wish that I had erred on the side of caution and wonder if the osteoarthritis I now have was caused or exacerbated by my having bled so much into my joints, and I have also developed other weaknesses as I've aged.

43. In 1974 I won a major cycling title (Welsh Junior Time Trial Championship) and the outlook for my cycling career was extremely good as I looked forward to participating in other championship races, However, my having been over-training whilst having haemophilia resulted in a major bleed. I can't remember having treated myself, but do recall that it all 'flared up' in the early hours of the morning and I'd had a massive bleed in the small muscles all across my abdomen.

44. This partially crippled me for months and I was hospitalised for some three to four weeks. Damage to the blood circulation in one of my legs, on a separate occasion meant that I had to use crutches for some time, and taken together these bleeds impeded my cycling for an appreciable period, and effectively put an end to what had otherwise looked to be a most promising sporting future.

45. I cannot now remember when it was that a dedicated regional haemophilia centre was established at the hospital in Cardiff, but I had to access my treatment materials from the same ward each time. I recall, from the packaging, that the Factor VIII I was given to use came from a variety of suppliers in the U.S.A. and Europe and I can remember product names such as '8Y' and 'Alpha,' but my recollection is incomplete and vague although I do recall these names together with Koate, Lister, Scottish, Haemofil and Profilate.

46. Each time I was restocked with Factor VIII I would be given an A4 sized sheet of paper upon which I was to maintain a record of all home treatment administered, including the batch numbers of the product used, the purpose of my use of it, and the amount. Whenever I returned to the hospital to re-stock with Factor VIII, I handed the sheet in and was given another. I do not know what happened to all of my records, but I have been able to secure copies of some of them, hence the detail I am able to provide (such as that concerning the product names, as per my paragraph 45 above).

47. I have always enjoyed country life, hunting, fishing, shooting that sort of thing, and cycling – which took me out into the countryside. Upon leaving school, I planned to go on to pursue a degree in applied biology, but was unable to do so until such time as I had a suitable chemistry qualification – which meant that I had to attend night school at the local college. As I studied, and occasionally worked for my father, I socialised in the local pubs.

48. I can remember having bumped into a boy from school in one of the pub's, someone I hadn't seen for a couple of years. He had been to University but had returned and was unemployed, unable to find a job even with good qualifications. His being unable to find a job, and not to be able to use his qualifications, demoralised me and my thoughts of higher education waned.

49. I tired of days spent idly socialising and walked the two miles from home to the nearby railway depot. Here I was told that as a fine looking fit young man, I could start working there as a freight guard as of the following Monday – I didn't tell them that I had haemophilia.

50. I decided not to continue with any further education, but joined the railway, undertaking three months training at guard school. Haemophilia wasn't holding me back and as a young, fit, active lad who enjoyed an outdoor life, working in the freight yard was perfect for me at that time. I'd rise at three or four each morning and worked ferrying coal from the South Wales Collieries to the marshalling yards and docks in Swansea and Barry.

51. I worked as a freight guard for a few years, it was a well-paid job and as a young man I enjoyed the fruits of my labours, out socialising most nights in Swansea. One evening, in October 1980, I went to a Halloween Ball in a nurses' home where I met my future wife. By Halloween 2021, we'll have been together for some 41 years. She has been immensely supportive over so many years now that I simply do not know what I would have done without her – but I didn't tell her, when we first met, that I had haemophilia, even though I knew her to have been a nurse.

52. A couple of years later, I suffered a major bleed and had to take a couple of weeks off of work, sick. I had used the same G.P., as had all of my family, for many years and he knew my condition and its treatment. He also knew that for me to declare haemophilia to an employer / potential employer may have caused problems for me, so he had always been economical with the truth when writing 'sick notes.'

53. Usually, I'd tell the GP and he'd write a sick note without the need for a consultation and citing some firm of injury but not a haemophilic bleed or mentioning haemophilia. Unfortunately, when this bleed occurred, he was away from the surgery and a different doctor wrote the note which I handed in to my employer without realising what it may have had written upon it – the doctor cited haemophilia.

54. Upon my return to work the following week, I found myself being chastised by my immediate boss, and sent to the company Chief Medical Officer (CMO) in Cardiff, not for having been off sick, but for not having told them that I had haemophilia. The people at the yard I worked in were very supportive and didn't want to lose me, but the CMO took a very dim view of things and made it quite plain that as a severe haemophiliac, running around a rail freight yard, jumping over rails and so on was not for me – I kept my job, but was confined to an office. Fortunately, a timekeeper's job in the yard office had become available and supported by the yard manager, I took the job, and made very good money having done so.

55. I was ambitious, and although comfortable in the role and with my working environment, and on good pay, I didn't want a time-keepers role forever. A vacancy arose for a depot clerk with the civil engineering department in Neath. It was an 8 'til 4 job, a pay grade higher than that which I was on, so I took the job. This proved to be marvellous timing as it came about a short while before my wife and I married in February, 1982 and bought our first house together – an added bonus was that whenever we may have needed building materials, I could source them from the yard.

56. Whilst engaged as the depot clerk I also became responsible for the workers timesheets. This meant that I was asked to relocate beyond Wales, to Bristol, which I didn't want to do, so they ended up finding me another clerical job with the railway, back in Swansea. This was effectively a regressive step for my career development, but I was able to maintain my pay grade. Instead of filing in forms, I was used to input timesheet information onto a then fledgling computer system. I was rather lucky with this, as it quickly became evident that I had an aptitude for this sort of thing, and the technical officer on site, who wanted to change roles, earmarked me to take his place.

57. Everything seemed to be moving in the right direction for me, professionally and domestically, I was settled into a well paid job which I enjoyed, had a stable relationship and our own home, and haemophilia was nothing more than an occasional inconvenience.

58. However, in around 1984 / 1985, I received a letter from Professor Bloom from the Haemophilia Centre at the University Hospital of Wales in Cardiff, who'd treated me since the elbow injury and my first use of Cryoprecipitate, and then Factor VIII.

59. Through the letter, Professor Bloom said that I must by then have become aware of media articles that had been published and / or broadcast concerning AIDS within the haemophilia community, as such articles were rife at that time. He assured me not to worry about it, but asked that I travel to Cardiff to discuss concerns as regards AIDS and related issues.

60. I went to his clinic, as requested, and he told me that I had the Human Immunodeficiency Virus, or HIV.

61. I was then invited to attend a meeting of at least fifty people in the same position as myself, held in the hospital lecture theatre – it was well attended by patients and people supporting them. I can still remember sitting in the auditorium looking down on Professor Bloom at the dais – it was a pretty gloomy atmosphere.

62. My wife, in particular remembers this event and the feelings of both horror an dread amongst those attending. Professor Bloom appeared to have gathered together all of the haemophiliacs under his care who had been infected with HIV alongside their respective partners. He discussed HIV and in particular the need for those infected us all to exercise great care in our romantic encounters, advising that we should not engage in sexual intercourse or even kiss one another.

63. My wife and I found his advice, such as it was, over dramatic and not at all constructive. It led to Ann and I having lengthy discussions, over a long period of time, as to whether or not we should have a family, but she was taking the contraceptive pill and so we continued having unprotected sex.

64. One of the concerns we had was that were we to tell others, with children, having had children of our own, then our children may have been isolated, shunned by their peers, so it was a real worry as we both wanted a family.

65. At around the same time, I can remember having discussed AIDS with my mother, who'd asked if I had been affected because of my haemophilia and past treatment. I told her that I *"was fine,"* which was what I had always done, I never wanted to cause my parents any additional worries, so even when I knew, I decided not to tell them – my wife, who had by then known of my haemophilia for may years knew, and agreed with me not to tell my mum and dad. For many years we didn't say anything about HIV.

66. Some years later, thanks to the technical assistant at the haemophilia centre who'd looked for my medical notes, I saw a blood test form for me from March 1983 on the back of which Professor Bloom had written, *"Unfortunately this young man has shared a batch of treatment with another haemophiliac who has since gone on to develop AIDS, and died. The prognosis for this fellow is not very good."*

67. This shows what was known of my situation, by those treating me, a full 18 months to two years before I was actually told that I had HIV. Until then, neither Ann or I had any knowledge or cause to suspect that I may have been infected with HIV despite the information circulating in the media – I was fit and healthy, notwithstanding my haemophilia, and surely not all haemophiliacs had been given HIV, had they? Neither of us thought I had or had even been exposed to HIV.

68. The delay may simply have been a result of Professor Bloom allaying any fears we may have held, but I should have been told, and tested, as soon he knew that I had been placed at risk.

69. The group meeting held in the lecture theatre wasn't all that helpful as we all had more questions than we would ever have been able to receive answers to in the time available, but very few people spoke as like me they were all in a state of shock - each of us having been told that we had HIV.

70. Ann and I went to see Professor Bloom in clinic. We sought advice on our starting a family and how HIV may impact upon that. We were effectively told, that were we to continue enjoying sexual relations, then with HIV I would die, and Ann would also die, possibly sooner than me.

71. To the best of my recollection, I do not think that my wife was tested for HIV at that time, or even offered a test – that came later, nor can I now remember if our children were subsequently tested for HIV, each had blood tests as young children, but I cannot now remember whether this was specifically for HIV or not.

72. GRO-C

73. In the late 1980's, blood tests revealed that I had also contracted a form of hepatitis. This was referred to at the time as being 'Non A – Non B Hepatitis,' something which we now know as Hepatitis C (also known as Hep' C and / or HcV).

74. My wife and I were told, in clinic, that both the HIV and HcV I have had come from a contaminated batch of Factor VIII I had used which had been sourced from the USA. I am not so sure, although I know that I religiously submitted my home treatment records – I received very little American Factor VIII, so perhaps I could have been infected through the British product used or even the whole blood given earlier in my life, I simply don't know and it doesn't really matter as wherever it came from, it was given to me by the NHS, and shouldn't have been.

Section 3 - Other Infections

75. I do not believe that I have been infected with any other viruses to HIV and HcV as a result of my use of NHS supplied whole blood or blood products. However, in about 2004 I received a letter from the haemophilia centre in Cardiff informing me that the post mortem examination of a person with haemophilia had revealed tissue infected with variant Creutzfeldt Jakob disease or vCJD. The letter told me that at some previous point in time we had both used a blood product of the same batch as that through which this person was believed to have become infected with vCJD, and that as such, I may have been exposed to it as well. I cannot now recall with any degree of certainty, but the letter may have been accompanied by another from the National Blood Transfusion Service, but I am unsure of this.

76. I had also by then been told that I had been exposed to Hepatitis B (also known as Hep' B and / or HbV) over a protracted period, basically since my first having been treated for a haemophilic bleed, and that as such I had most probably developed a natural immunity to the virus. I'm not sure what this actually means, but am intent on discussing the issue with my current consultant, Mr. Peter Collins.

Section 4 - Consent

77. Consent for the treatments and blood tests I had until adulthood had always been addressed by my parents, in particular my mother. She took an active role in the decision making as regards my healthcare, albeit that with a 'doctor knows best" approach she merely accepted that which may have been placed before her. I had absolutely no idea where blood that I was given had been sourced from, and I doubt if she did either, or even asked. I just recall that everything began with bottles of blood which they hooked me up to, I have no idea what we may have been told as to 'why' this was necessary from those times.

78. On a number of occasions over the years, as an adult, I have consented to take part in various research programmes or projects related to the different types of treatments given as regards my haemophilia, and signed papers to this effect. I am pretty sure that my mother would have allowed this when I was a child, had she been asked. We both had a vested interest, as I still do, in helping research to improve the treatment of this condition.

79. As a person with haemophilia, I have become accustomed to having to submit to regular blood tests for which I have always given my consent. All the same, I have never been told of the specific tests which are being undertaken, what my blood is being tested for or why, which includes testing for HIV, HcV vCJD or anything else. However, I must confess that when attending consultations and seeing the doctor pull out my notes with previous test results in them I was never overly interested in seeing them.

Section 5 - Impact

80. My having been infected with HIV has had a profound impact upon my family and I, impacting upon many different aspects of our lives. The HIV diagnosis was closely followed by that of HcV and then of more recent years, vCJD exposure. I cannot emphasise how much this plays on your mind, one thing after another – I thought that I was dealing with my haemophilia, and dealing with it well, working, having a home, a wife, living a normal life then HIV, Hcv and vCJD. I cannot state strongly enough how this impacts upon you and those close to you, psychologically, as you are always wondering 'what next?'

81. My wife, family and I have just lived through the global Covid-19 pandemic, yet throughout that time I have yet too see any advertisements as shocking and worrying as those which were used in the 1980's regarding AIDS, an ailment that was portrayed as an incurable epidemic that could impact upon us all with a falling tombstone being used alongside projections that millions would die. It left you worried sick and fearful of identification as someone with HIV / HcV or even just haemophilia to which both were associated.

82. When I married my wife, in 1982, I had the physique of a professional sportsman, appearing like a rugby player with strong, muscular broad shoulders. Prior to the HIV diagnosis my wife began to notice that my musculature was degenerating. In around 1983 / 1984 I travelled to see my sister who queried where all my muscles had gone? We all began to fear the worse, but didn't think of HIV until Professor Bloom's letter arrived, calling me in.

83. In spite of haemophilia, HIV and HcV, I remained well albeit that my physique slowly fell away to a noticeable level until about 1996 when my overall health began to deteriorate. By then I was farming, and was bailing hay one day, using a tractor when I blacked out and had to be helped down by a friend. Following this, I was placed on treatment with the antiretroviral drug Azidothymidine, or AZT.

84. By 1997, the regular tests I had revealed that my CD4 count had dropped whilst my viral load was increasing. A CD4 count is a measure of how well, or not, your immune system is operating. I was informed by Dr Desani that my HIV treatment (AZT) was being impaired by my HcV infection and that the hep' C would have to be addressed if I was to avoid the HIV worsening.

85. Dr Desani told me of an experimental treatment that may just do the trick, and for which twenty volunteers were required. I volunteered although I didn't really feel that I had much of a choice.

86. As a consequence, in August 1999 I commenced a six month course of treatment with both Interferon and Ribavirin which I self-administered at home. Just a week later, I went into a real fog, sometimes not being able to think straight or knowing what was going on. I was really unwell on these two drugs for about six weeks, although with the side effects those six weeks seemed to me to be a lot longer. I resorted to shutting myself away, sitting in a darkened room with the curtains drawn and as I had been brought up to do, just got on with it. Then one morning, as if a switch had been 'flicked,' I found that the fog had lifted.

87. Every two weeks I had been going into the hospital haemophilia centre for my blood to be tested to monitor my progress. This returned positive results and some eight weeks into the course I returned my first negative Hepatitis C result, but I remained on the course of treatment until January 2000 – I continued to return negative HcV test results and have done so ever since.

88. I am told that I still have the Hep' C virus, but that it is inactive, but I continue to be tested, now annually, as Professor Collins has told me that whereas it is a rarity, it is documented that the virus may reactivate. Fortunately, this is a rarity and my liver, which HcV infection impacts upon in particular, is in a stable condition.

89. HIV and Hepatitis C infection has adversely affected my ability to cope with stress over the years and as a result I now try to live my life in as stress-free a situation as possible.

90. My wife vividly recalls incidents of the past where she found me being tearful or of a low mood, both of which were wholly out of character for me. Some of this I attribute to the conditions themselves, some to their psychological impact upon me, and some too the medication I have had to take to treat the viruses. I also find that I can be irritable and easily frustrated, especially when tired and find that I cannot do things.

91. Once clear of Hepatitis C, I was able to access the various treatments for HIV which had by then been developed and to which I responded well. However, I continued to suffer from exhaustion and a general 'brain fog.'

92. My family and I were due to travel to New Zealand for a holiday and so I discussed my problems with the lead pharmacist at the hospital who suggested that I come off of the treatment I was receiving and 'see what happened.' I did and found that both the exhaustion and brain fog stopped – but my viral load increased and CD4 count dropped as a result. I was then put onto a different medication regime and now take only one tablet per day. My CD4 count is stable (resting somewhere between 450 and 500, apparently).

93. Over all of these years of living with HIV and HcV, I feel that I have effectively had the equivalent symptoms to those of Long-Covid. I can remember going to see Professor Collins and another Consultant Virologist about it as once 'clear' of Hep' C, I had expected to return to my former state of fitness, but this hadn't happened and I can't help but feel a little old and decrepit! The virologist more or less told me to 'man-up' which made Ann extremely angry as she knows only too well how determined I am, and have always been, to push on through any obstacles I may encounter, no matter what.

94. I have found it particularly depressing and demoralising not having been able to return to my former self. For some twenty years I have had to deal with lethargy, exhaustion, muscle weakness and brain fog on top of haemophilia related issues. I continue to suffer from excessive and unexplained sweating, problems with my pallor where I just look ill all of the time, waves of exhaustion and erratic moods. Whereas the HcV virus appears to have been deactivated, its legacy remains.

95. Both Ann and I thought that some of her nursing friends may have guessed what was going on, that I had contracted HIV, but none of them ever said anything, and we didn't tell anyone for fear of the stigma associated with the condition. It was very isolating for us both and emotionally stressful, particularly when we had been looking to start a family as I had been diagnosed.

96. Our peers were all starting families and we wondered of we should take the risk. We considered all of the options available, which were limited – basically, natural conception or In-Vitro Fertilisation (IVF) if we wanted a child of our own. Such developments as 'sperm-washing' simply weren't then available. We spoke to Dr Desani about it – he had operated the haemophilia clinic for a couple of years, following the death of Professor Bloom and prior to Professor Collins having been appointed.

97. Dr Desani assured us that if we had been having unprotected sex over a protracted period, as we had, without HIV having been passed by me to Ann, then there was not a significant likelihood of my transmitting the infection to her or a child. He was a very supportive clinician who at all times appeared to be both protecting us and ensuring we had access to any treatment that may assist.

98. All the same, we didn't start our family for some eight years following my diagnosis as we were both, and me in particular, worried of the risk of either passing on the infection to any children and / or our not surviving ourselves to see them grow up.

99. This was really hard on Ann, who was the last within her friendship circle to have a baby and there was an appreciable gap between our first born and those of our peers. She had also specialised as a nurse in midwifery, which didn't help, as she was forever delivering and handling other people's babies whilst battling with the decision as to whether or not to have a child of her own.

100. In the end, we went ahead and in 1990 Ann fell pregnant, later having our first child on the ward upon which she worked. Neither Ann or the child had caught HIV from me. All the same, the child had to be tested, which was worrying for us both, but fortunately she was clear.

101. Ann was a midwife, and one aspect of her work was to assist and advise mothers as regards breastfeeding, which all mothers were encouraged to do if at all possible. GRO-C

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103. All the same, we had a fit and healthy daughter, and although always advised against having unprotected sex, we went on to have two further children,* both sons – GRO-C

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* 1 girl 1 boy (three children in total)

104. Our children have always known of my having haemophilia – we made no secret of it, with them but in their earlier years, we weren't as open as regards HIV.

105. My wife and I had acquired a small holding which I farmed and where minor cuts or grazes were commonplace. They learned not to go anywhere near me if I had a cut, because of my haemophilia (not HIV), whilst I dealt with it, and I was always careful to keep myself away from them if I had a cut, as a precautionary measure. I was also always careful to keep my medication and in particular sharps and used sharps away from them. That aside, and with the precautions taken undoubtedly enhanced due to my HIV status, I didn't act any differently around the children or Ann, life went on 'as normal.'

106. The risk of infection aside, due to the stigma associated with HIV, I avoided telling any other friends and family of my status. I felt that my parents had suffered enough with my having haemophilia, and decided not to tell them as I didn't want to cause them further worry. We didn't tell any other family members or friends and confided in one another.

107. Living in a small community, had word of my condition been known, we were both fearful of the consequences, not necessarily for Ann or I, but for our children especially as adverse public reactions to people with HIV had been reported in the press. Whereas this protected our children, and us, it meant that we had no one to talk to ourselves.

108. We avoided telling the children until they were each about eighteen years old as we didn't want them to share it with friends and thereby see the news spread. Whenever I had been taken ill, and people asked questions, it was attributed to my having haemophilia, or issues with HcV treatment, never HIV as we felt these would attract less ill-informed judgement. Only recently have I become sufficiently confident to have told a few friends of my having HIV, but very few.

109. It is all too easy for ill-informed people to jump to conclusions and deliberately or not cause distress. Around about the time of my diagnosis, I had been working at the railway station in Neath when one if the AIDS related adverts was broadcast.

110. My manager, someone who knew of my haemophilia but not of my having HIV, promptly declared for anyone within earshot, *"watch your arses boys, Jonny's here!"* Homophobia, haemophilia, and AIDS had become very much muddled together and although I am sure that he had made his comment in a sense of humour, male 'banter' amongst workmates, it was nonetheless upsetting and worrying, and an attitude that was one of the reasons behind Ann and I having kept ourselves to ourselves.

111. With all of the stigma then associated with HIV, I decided to take a redundancy package based upon my having haemophilia, but that was just a convenient excuse. I commuted a major part of my pension as a lump sum payment, and Ann and I used that to purchase our home.

112. Having done this, I lost a well-paid, stable job and moved onto an ill health pension (I now receive £290- per month). Having always had a desire for rural living and a country lifestyle, we took a smallholding and I became a farmer, but that didn't make much money, it was a lifestyle choice for me, more than anything else.

113. My wife's income as a midwife wasn't good either, and as the children were growing up, we didn't have much money between us so they had to be content with second-hand clothes and toys.

114. Returning to the issue of stigma, AIDS and homosexuality, some neighbours of ours once refused to use the local pub' where they believed the barman to have been gay. There was an occasion when the bar was vandalised by people ranting and raving that they *"didn't want AIDS"* in their village. It was a terrifying thing to have witnessed and an extreme and vicious case of prejudice. Ann and I worried for the consequences had my condition been known.

115. I know that it came as a terrible shock to Ann when I was diagnosed as having HIV. We'd only been married for two years when the news of the infection was given to us and it has had an immense impact upon us together with worries for the implications of this disease for me and us as a couple and parents. Then there was, and remains, the additional impact of HcV and the symptoms of this infection and the side effects which its treatment had. As a couple we have also had to be extremely cautious during the current Covid-19 Pandemic, as I am immune-suppressed and prone to infection, any infection that may be 'going around,' let alone Covid-19 and its dire consequences for vulnerable people.

116. Having been diagnosed, first with HIV and then with Hepatitis C, my consultant warned us that my life expectancy could be somewhere between two and five years, then extended to ten years as I failed to succumb to either illness as had been initially expected. At the time of the 2 – 5 years expectation being given, I was advised by the doctor in Cardiff to 'give up' work and to consider the quality of life I wanted to live in what time I had left – that was when I took his advice, went onto sick leave and eventually retired on an ill health pension.

117. Having 'gone sick,' and before I retired, I received a letter from my employers requesting that I attend the regional health officer in Bristol as they clearly thought that I had been malingering and wanted to get me back to work, or dismissed.

118. When we met, I was told that the doctor had received a letter from my admin' manager. I told him that I had severe haemophilia, and he was very sympathetic towards me – prior to working for the railway, he had apparently worked as a local G.P. who had three patients with haemophilia in his care. He understood my circumstances, which I had not been expecting and which came as a welcome surprise under the circumstances, and advised that I return home and stay sick, which I did.

119. Had I have remained with the railway, within their IT Department, as a technical manager I would have been placed on call which meant that I'd have to leave home at anytime of the day or night. It was a job which although I was more than capable and comfortable with, wasn't ideal for my personal circumstances. At the time of my going sick, Ann and I had bought a 39 acre smallholding, keeping both sheep and cattle, so I settled for a rural life, a lifestyle I enjoyed.

120. Ann's career also suffered as a result of my health issues. When we met she had only been qualified for some eighteen months and was moving on into midwifery. When I was diagnosed, GRO-C GRO-C although she went on to work as a midwife for some fifteen years, knowing the risk she may have posed to others, she avoided working in areas, such as the theatre due too the invasive nature of its work, to reduce risk which served to limit opportunities for her.

121. Her avoiding certain aspects of midwifery work was difficult as she and her colleagues were required to work on a rotational system, and in each area of midwifery. She worried that she may have lost her job if she declared that I had HIV, so she didn't, but then she faced stress as she felt her colleagues may have thought that she was avoiding certain aspects of the job or that she may have been considered less than competent in certain tasks.

122. I have also found it very difficult to have seen so many of my fellow haemophilia patients of the centre in Cardiff centre pass away over the years. It seems that each time I returned for a clinic appointment, and asked after anyone, I was told that they had died. Within a period of just two years many of them had succumbed and it made me reflect on just how lucky I was. At the same time I was concerned for how long I may have left, as my life expectancy had been so fluid. I had, and have to this day, what has been termed as 'survivors guilt.' We had all been given the same infections, from the same sources, yet our prognosis remained varied and of something like 1,200 infected haemophiliacs across the United Kingdom, only 289 of us remain alive.

123. Both opticians and dentists enquire of my HIV and HcV status, but I have never faced any problems securing treatment.

124. Securing life insurance has been an issue, initially as I had haemophilia then once HIV and HcV were found, it was nigh on impossible to get. Things have eased a little over the years, and by way if example, HIV is no longer looked upon as being a problem by travel insurance providers. Once I found a company who were willing to insure me, I have used them ever since, you can't 'shop around.'

125. When we bought our second property, and life insurance was required as an integral part of our securing a mortgage, this had to be Ann only as due to haemophilia, I couldn't get life insurance.

Section 6 - Treatment / Care / Support

126. Since we got together, my wife has always accompanied me to any medical appointments, but in my late teens, I used to go alone if my mother wasn't with me. I began to refuse to go to the hospital in Cardiff for haemophilia check-ups as it was a real trek to get there from Swansea, I didn't drive and had to use patient transport. Once there, Professor Bloom was seeing so many patients that despite your appointment time, waiting time to see him often extended to two or more hours each time.

127. Having refused to go, because of the above situation, I was sent a threatening letter in which the hospital said they'd withdraw my supply of Factor VIII if I didn't attend.

128. These were technical issues though, problems which came about as Professor Bloom was inundated by the sheer number of haemophilia patients placed under his care. Personally, I was always content with my haemophilia care under Professor Bloom who always seemed to know his subject very well, but I was less satisfied with his approach to me once HIV had been diagnosed.

129. I know, from the note I have seen on the back of a blood test form, that he knew I had HIV a long time before he told me. I do not feel that I have was given adequate information about the condition, and then there was the draconian advice for Ann and I not to have sex or even embrace one another and not to have children.

130. I believe that Professor Bloom never had any form of malicious intent in the way in which he addressed us, but I think his manner could, and should have been far more sensitive, but whereas he seemed to know everything about haemophilia and was very comfortable dealing with that, he did not seem so comfortable around HIV.

131. The Haemophilia Centre at the University Hospital of Wales has been very helpful. When I had been attending the Morriston Hospital in Swansea, there had been a group of young people there, all with different problems, few if any with haemophilia like me. The dedicated centre was more of a community and Dr Desani in particular was very supportive. Whenever anything was wrong, I could source help from the different departments of the hospital, aided by Dr Desani who has since been replaced by Professor Collins.

132. Until about ten years ago, visiting the haemophilia centre was like walking into a friends' kitchen – everyone was there and you knew who they all were, staff and patients alike, it had a homely, family feel about it. Now, sadly I began to feel like a stranger, so with the travelling to Cardiff becoming more and more taxing, I decided not to go there anymore but attend a clinic at the Singleton Hospital in Swansea instead.

133. I have only recently been offered any firm of counselling or psychological support to assist me dealing with my situation. Ann believes that this would have been most beneficial to me in the past, many years ago, but it was never made available although a social worker from the centre did once come to visit us, but I didn't find her at all helpful.

Section 7 - Financial Assistance

134. I first became aware of the Macfarlane Trust through a fellow haemophilia patient attending the hospital in Cardiff. As a haemophilia patient who'd become infected with HIV I applied for assistance and received a lump sum payment of £60,000-.

135. I believe that payments from the trust may have varied dependent upon an individual's circumstances, but I don't know this for a fact. Ann and I used the money on our house, and I also received various other payments, grants of financial assistance for specific projects such as insulating our home. I only ever asked for help when absolutely necessary.

136. I found the application process straightforward, and the trust administrators very efficient. Initially they only accepted applications from haemophiliacs, but I believe that the scheme was subsequently broadened to help others, people without haemophilia, but finding themselves in a similar position having become infected through no fault of their own whilst being treated by the NHS.

137. A friend in a similar situation as myself, invited me to attend a Haemophilia Society meeting in Swindon. I went and found it interesting to see the different attitudes of people and the perspectives they held as to their lives and expectations to the future. I found, to my surprise, that some people with haemophilia had never worked and they, and others, were wholly reliant on the financial assistance provided through the trust.

138. Many of those there were fatalistic and some had blown everything they'd been given on fast cars and / or lavish living as they hadn't expected to live very long – consequently they had made no investment in their futures.

139. The Macfarlane Trust was succeeded by the Skipton Fund. I have never formally applied to the fund as they appear to have passed my details on, but I did receive an additional payment as regards my having been infected with HcV, which was again administered through Macfarlane. This was a single lump sum payment, but I cannot now remember the amount.

140. Macfarlane passed to Skipton and then the Wales Infected Blood Support Scheme (or, WIBSS) came into being and I began receiving monthly payments through them.

141. WIBSS also have wellbeing groups to assist with mental health issues, and they appear to have actively encouraged people like me to apply for additional financial help if we had mental health issues. However, the offer was accompanied by a warning that were they (WIBSS) to discover that there were no mental health issues, then any funding would be retracted. They also offer other support as necessary.

142. On one occasion, I attended a hydrotherapy session with some fellow haemophilia patients. Whilst there, I was asked by another patient if I had applied for the mental health grant of £22,000-. I hadn't and not thinking that I had any mental health problems, wasn't going to, but cannot help but think that the system is open to abuse and some people have undoubtedly made false applications and no doubt spent the money already. All the same, Ann believes that my mental health has suffered over the years and with the worry and stress I have experienced, would have to agree with her.

Section 8 - Other Issues

143. As previously mentioned, at some point in time in the 1990's, I was involved in the HIV litigation which took place in the USA. I hired a solicitor (locally), and sought access to my medical records to support a claim. Most of what I received as a result of my request were laboratory test results, some annotated as regards HTLV-III, but back then that didn't mean anything to me and I would only have been interested had I known what it was, I didn't then know that HTLV-III was actually HIV. I saw the records we were given, which weren't full, but they remained with the solicitors, I do not have them myself.

144. This came about following H.M. Government's decision not to implement Recommendation 6 of The Archer Report, and was known to me as the LCHB Litigation (which I recall as having taken place during 2009 / 2010). In the 1990's there had been an effort made to consolidate various individual claims, and myself and others were advised to register with a local solicitor, but the action made no headway and I have not kept any records of the same.

145. Interestingly, following data which became available as a result of an Infected Blood Inquiry sourced video, I have been able to trace a known infected batch number, a batch from which I was given a blood product in 1980 or 1981.

146. From the records I have been able to secure, I have found a note stating, *"Has had same batch no. as* GRO-A *"*

147. Knowing what I do now, whilst looking back at my treatment records, such as I have been able to locate, I find it quite startling to see the numbers of donors / packs involved in each single treatment of Cryoprecipitate.

148. I am glad that after so many years a public inquiry is being held and regret the fact that this didn't happen many years ago, as so many people have now passed away. Sadly, in my view, money and politics dictate everything, and no doubt the problems which caused this scandal will be found in one or the other if not both, but I hope that once the Inquiry reports, all of those affected by contaminated blood and contaminated blood product use will receive compensation.

149. Having said that, more than anything, I just want the truth to be revealed and made public. I hope that lessons can be learned, at every level and in particular for the operation of blood transfusion systems and the screening of blood and blood products. GRO-C

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Statement Of Truth

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

Signed: GRO-C

Dated: 11th March 2022