

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MR STUART GREGG

I, Mr Stuart Gregg, will say as follows:-

Section 1. Introduction

1. My name is Stuart Gregg and I live at GRO-C Worcestershire, GRO-C I live here with my partner of 24 years, Emma, together with our three children GRO-C My mother, Janet, and my sister, Donna, live locally. My father passed away in 2008.
2. I now work a zero-hours contract job, which provides flexibility for my poor health. It has only been in recent months and, in particular, following the increase in monies from the EIBSS that I have had financial security. This means that I can manage financially even if I am unable to work due to my poor health. The previous 25 years have proved to be a financial struggle. In the past I have studied and worked at the University of Birmingham until my health, due to the infections, curtailed my studies and, as a knock-on effect, my career.
3. **Exhibit WITN1252002** is a time line which I produced to assist with some pertinent dates for this witness statement.

Section 2. How Infected

4. I have severe Haemophilia A. I was diagnosed at approximately 18 months. There was no history of Haemophilia in my family; it was a genetic mutation that caused my Haemophilia. I have always bled heavily and was frequently hospitalised as a child with regular muscle and joint bleeds.
5. As a child I was treated at the Birmingham Children's Hospital, under consultant Dr Frank Hill. Dr Hill had the nickname of "*Dr Death*" amongst his patients which was somewhat ironic. Dr Hill had spurious methods of care and treatment for his patients; he focused on treating heavily, putting children on constant bedrest and used only one product, Armour, throughout the period when I was infected. I am not sure whether this persistent use was incentivised or whether Dr Hill had other reasons to go down the Armour route.
6. Dr Hill was the main consultant but I was also treated by Dr GRO-D. The main staff nurse was Sister GRO-D.
7. In retrospect, I can now see that I was given infected blood products on a near weekly basis over a long period of time. **Exhibit WITN1252003** is an extract from my patient record book which confirmed the dates on which I received Armour.
8. By the time I was infected, these products were widely known by professionals to be contaminated and should not have been used in any capacity.
9. I have never had a "*life-threatening*" bleed which necessitated treatment.
10. I was a child when I was infected with the contaminated blood product Factor VIII. My mother was not given any advice as to any risks. I firstly received Cryoprecipitate, but then this was recalled and I was given Factor VIII. My mother was told repeatedly that these products were safe and that we should keep using them. In the mid 1980's, my mother attended an Annual Haemophilia Conference, chaired by David Walters. She had a one-to-one conversation with an Armour products representative who advised my mother that these products were safe to use. All the parents were assured that these were indeed "*completely safe*", as per the words of the Armour representative. They were also advised that these products came from "*researched people*" whom they knew the history of and the parents were assured that as such the donations were safe.

11. In 1984, Dr Hill called a meeting at the Queen Elizabeth Hospital and stated that the NHS could no longer provide an adequate blood product service to Haemophiliacs. The parents of Haemophiliacs were told to lobby their MP's. Our MP was Michael Spicer at the time who advised that there was no funding to help. However, nothing was mentioned in relation to the contamination of blood products.
12. I was a minor at the time of infection. However, as I am aware, there was NO information given about possible infection through the use of blood products. My mother was told repeatedly that they were safe and that we should keep using them. Only in retrospect and researching documents, such as Haemofact newsletters, I realised that the community of Haemophilia Doctors were aware that HIV infection (or HTLV III as it was called then) was happening. However, in those documents, it was still stressed that patients should continue using blood products.
13. I was infected with HIV in or around 1984 and it was prior to this that I was infected with both Hepatitis B and Hepatitis C. **Exhibit WITN1252004** is a letter dated 16th February 1994 from Consultant Jonathan Wilde at the Queen Elizabeth Hospital to whom it may concern. This letter confirmed that I acquired the HIV virus from infected factor concentrates which I received for bleeding episodes in the past.
14. **Exhibit WITN1252005** is a letter dated 7th February 1985 from the School Medical Officer to the Haematology Department which confirmed that I was found to be hepatitis B surface antigen.
15. **Exhibit WITN1252006** is a letter dated 30th May 1990 from Jennifer Evans to Dr J Marsden which confirmed that I was Hepatitis B positive.
16. **Exhibit WITN1252007** is a letter dated 21st June 2001 from Consultant Jonathan Wilde to Dr K Ashbridge which confirmed that I had Hepatitis C.
17. I was never sat down and told about having HIV; rather it became apparent over time. I remembered watching the television in or around 1987 and seeing the adverts with the iceberg/gravestone and the phrase "*Don't Die of Ignorance*". I remember thinking that it was about me and that this was what was happening to me. I remember thinking that I hadn't been ignorant but that I was going to die. The only time I really remember talking with Dr Hill about my HIV was when I was in a normal clinic appointment. He would tell me that my

cd4 count was the only information or gauge which he had about my HIV and at each appointment it kept dropping. The only advice that I had from Dr Hill was to use a condom if I started a sexual relationship. I would have probably been in early high school at this time. Prior to that, I always remembered my mother telling me to clean up my own blood spillages and I was okay with that. I knew that it was because there was some sort of risk and I liked to be in control so I was fine with my mother's advice.

18. Using a condom and cleaning up my spillages were the rules that I adhered to stringently as the possibility of infecting others became a real weight on my shoulders. This had an effect on my ability to have normalised relationships in younger years; I never went around trying to form normal relationships.
19. Nobody sat me down and told me about my infections; it all transpired in a piecemeal fashion. The medical professionals knew about my infections years before they spoke to my mother or I about them. My mother received this information from talking to other mothers and from the Ward Sister who said "*Isn't it sad about the boys*". The hospital seemed to actively keep patients apart to avoid any possible interactions, rather than actually trying to encourage support and help.
20. I was given absolutely no adequate information to help me understand and manage the infections. The only information I was given, which was some years later, was to try and stop me from transmitting the virus to others. I was never told anything about my own health or how to assist me in my battle against the infections. I was never told about the route of disease progression, nothing about diet or nutrition and nothing about potential avenues of support. Looking back I was completely in the dark; the hospital held all of the tools and chose not to support or help me in any way.
21. Information about my infections should have been provided to me earlier; there are notes in my medical records saying that a sample from 1984 was HIV positive, yet I was never told anything. I was never really told anything for years. The way in which I became empowered and knowledgeable about HIV was in 1998. I started combination therapy in 1997 and I came alive a bit and started my university course in health and social care and it was then that I became really interested in HIV and started to learn about the virus and how it manifested and about various treatments. I also undertook voluntary work at an HIV centre and I undertook courses via NAT and NAM and I then used this knowledge to research HIV further in my MA and PhD.

22. In relation to my views as to how the results of tests and information about the infection were communicated to me, well, it just didn't happen; so how can I have a view? I now resent the way I was treated, however, at the time and being so young I did not understand how things should've been done properly. Furthermore, my blood tests (cd4) were given as the only barometer of my health and when these got to 10 (they should be above 700) I thought that I was preparing to die. I had not been told of any possible treatments; I had been told to prepare to get ill and die.

Section 3. Other Infections

23. I received blood products that may have been contaminated with vCJD (Jakob-Creuzfeld disease). Whilst I was in hospital as a child, possibly during seroconversion, I was allowed to be exposed to another patient with TB and I then became very ill with TB.

24. I also believe that I have been exposed to new-variant CJD, this was partly because I was refused access to recombinant synthetic products for many years and had to continue to use blood products which continued into the 2000s. I have letters of appeal that I sent to my health authority which said how important it was for my health prospects to be put on recombinant factor. It is evident that repeated exposure to infected blood products is much worse than a one-off exposure.

Section 4. Consent.

25. I was treated and tested without my knowledge and I was treated and tested without my consent. I could not give consent without knowledge.

26. I was a minor and things were done without my parent's knowledge or consent.

27. I believe that many tests were carried out on me without advising of the full motivation for those tests.

28. I believe that I was used for the purposes of research. Our community, the co-infected, was the perfect cohort on which to carry out research. We were a stable, adherent and compliant cohort. We were generally risk averse and had non-chaotic lifestyles. We existed

in a patriarchal medical system. We comprised the perfect material for the purposes of research. **Exhibit WITN1252008** is a letter dated 11th January 1982 from A. L. Bloom and C. R. Rizza from the Oxford Haemophilia Centre to all Haemophilia Centre Directors which detailed some research proposals.

29. **Exhibit WITN1252009** is a letter dated 17th August 1990 from Dr Hill to my parents which requested that I participated in a study which the Medical Research Council had agreed to finance.

Section 5. Impact

30. It is almost impossible to give a detailed account of how this has affected me mentally and physically. HIV, Hepatitis C and Hepatitis B have informed my whole life as I was infected at such a young age. The physical effects have been tough and at times I have been close to death. I have suffered throughout my life as a result of this.

31. I am tired now; I am tired of fighting for answers and I am tired of this being my whole life. However, it has informed who I am from a very early age and it is inescapable. It has moulded me as a person.

32. As a result of my infections I have also had many other issues such as damaged liver, damaged lungs, clinical depression due to Hepatitis C treatment, hospitalisation due to the side effects of the HIV drugs and I was close to death before starting the HIV anti-retrovirals. I endured all of these physical symptoms together with an intense psychological impact which caused even more problems throughout my life.

33. The mental side effects have been harder, at times, to contend with. These are the effects which have prevented me from leading a full life in any meaningful way. It is impossible to change how you think about things when you have been so close to death and having no future; you simply cannot reverse that and then expect everything to be fine again.

34. I am sure that I have some "*survivor guilt*" because there are only about 15% of the co-infected haemophiliac community still alive. I am pretty sure that I have something similar to PTSD, as whatever I am doing I often zone out and reflect. I know for definite that my head has been screwed up since the "**chemical depression**" which followed my Hepatitis C

treatment in 2010/2011. This has had the biggest impact on my life and changed my mental stability irrevocably.

35. As a result of receiving infected blood I have had various symptomatic problems such as a lowered immune system for many years which unfortunately took over a decade to start getting stronger. I had many complications from my HIV medication which ranged from basic nausea through to things like haematuria which hospitalised me.
36. In the early days in or around 1989/90, I was put onto AZT at a high dose. This made me sick and I was not particularly compliant with the regularity of taking the drugs. Later on, circa 1991, I was put onto another new drug called Didanosine (DDI). This consisted of taking huge tablets and again made me feel sick. Similarly, I was not particularly compliant in the taking of the tablets. In hindsight, I unknowingly made good decisions not to take those medications properly. There was something about the way in which these medications were discussed that seemed a little half-hearted. I was much more compliant with my future medications.
37. I have been on a few drug regimes since 1997 in respect of my HIV; these have mainly proved effective, however I have had many side effects since 1997, including hospitalisation with haematuria, but you learn to live with the constant sickness and feeling tired all the time.
38. I commenced a 48 week Interferon and Ribavirin treatment for my Hepatitis C in 2010/2011. I tried too hard with the treatment. I suffered terribly and endured skin problems, loss of appetite, sickness, headaches, insomnia, no interest in life and low mood. I was taken off the treatment at 46 weeks due to chemical depression. Unfortunately the chemical depression has altered my mental outlook and capability since then. I never fully recovered from that. The treatment was pernicious and I was never really given the full expectation of how bad it could get. I was told that it was like having flu and that you would be normal again 6 weeks post treatment.
39. The mental and physical effects of the treatments which I received are that they have informed my whole life. I have suffered endless problems; you can say that these treatments have kept me alive, however sometimes it feels as though enduring the treatments was not worthwhile due to the pain I have been left in. Sometimes I think it hasn't been worth it for the pain I am left to feel.

40. Luckily I have a strong family and my infections have been easier to deal with as a result of this. I was so young when I was infected and I have grown up knowing only infections. When I entered into relationships I ensured that HIV was discussed at an early stage. My HIV was never really talked about with my family before I left home; it was known about but not openly discussed. That was a hangover of the quiet attitude you had which was as a result of the more widely held stigma surrounding it.
41. My partner Emma has always supported me and never put herself first when it came to living with these infections. However, it had a massive impact on starting a family; we had many rounds of IVF. This caused a lot of emotional problems when those cycles failed together with physical harm to Emma who had to endure repeated cycles of egg collection.
42. Our family took many years to create, it also cost us approximately £20,000 to fund the IVF and to minimise any risk of transmission of my infections. I have always felt that this was wholly unfair and that we shouldn't have had to use our life savings to fund this given the mode of infection.
43. I was trying to do the right thing by Emma and our future children; which would have saved the NHS hundreds of thousands of pounds when you think what they would have had to spend if, God forbid, Emma and all three children had been infected. However, the NHS failed to assist us with the funding and when I appealed this decision the answer was the same.
44. I think that it has been very hard for Emma and my mother. Emma had to suffer with the IVF and had to comprehend a relationship with someone with no long term future. However, the Hepatitis C treatment was probably the worst time for Emma and my mother as I developed chemical depression whilst on this treatment and have unfortunately not recovered from this.
45. My children do not know about my infected status. I have been with Emma for 23 years and our situation has shaped who we are. Emma has a '*glass half empty*' attitude, and I try to adopt a '*glass half full*' attitude. We were fighting to pay for the IVF treatment and it felt like a battle. Emma recalls that early in our relationship a condom broke which was extremely worrying, but thankfully she was not infected. Emma acknowledged that my Hepatitis C treatment was the lowest point of our relationship. At this stage we had a young family and

a new born baby and Emma was unable to provide me with the emotional support I required. We have learned to live and coordinate as a family, but it does not mean that it is always easy. We remind ourselves that there are people who have more difficult things going on in their lives. We have a strong relationship and maintain our focus together in the right direction.

46. My infections were not something which I could turn on and turn off and they have had a life long impact on every chapter of my life. There was and is no "*magic pill*". I don't generally make plans and I do not look forward to anything.

47. Because of the stigma of HIV there was always a golden rule that we didn't discuss it with other people outside of the family. It was only when I became older and more independent that I told people in my life, however, I have only ever told a handful of people about my status. Even now my wider family do not know, my partner's family do not know and many of my friendship group do not know.

48. I quite like the fact that people love me for who I am. However, I do feel that they only know a small part of me because they don't know about my infected status.

49. The people I have told have always been great about it and very supportive. However, I have carefully selected those people and I would expect their response to be as such. My mother will remember better, but in the 1980s when I was at middle school, one of the parents told the local press that a boy in the school had HIV. This was at a time when people were being ostracised and isolated because of the stigma. Luckily my mother was able to deal with this at the time and she was able to shield me from a lot of the stigma that would have come my way. My mother also assisted by being discreet and just "*carrying on as a normal*".

50. Hepatitis C was not the main problem when it came to stigma. I did not even care about my Hepatitis C infection until the 2000's because I was always expected to die from HIV. In fact there was a big issue between the co-infected and mono-infected haemophiliac communities. There aren't many living co-infected haemophiliacs left and therefore our voice is a lot quieter than the voice of the mono-infected community. I often hear terrible things from the mono-infected community about the co-infected community for example that the co-infected have been better supported, but the mono-infected community have forgotten a few things, namely:

- a. Nearly 85% of the co-infected community are dead, compared to about 20% of the mono-infected community.
- b. They have forgotten the days in the 1980s when HIV was a dirty diseased stigma and a total death sentence.
- c. They have forgotten that they were glad to only get Hepatitis C and not HIV as well.
- d. They have forgotten that they would not even admit to having haemophilia in those days in case people assumed that they had HIV.

51. There are even people who have never had treatment or been ill, yet they still think that the co-infected community have been "*lucky*". This is one of the elements that makes me most angry. I don't want the voice of our community to be lost. The co-infected community as a whole have gone through terrible illness, pain and discrimination; whilst some in the mono-infected community have not. It is not comparable to say that, as a whole community, they have suffered anywhere near as much as us.

52. My education suffered because of my infections. I had pretty much given up trying at school before I sat my GCSEs. I was naturally a very able student, so I was able to pass my GCSEs without trying. However, my A-levels turned out badly. I did not see the point of working hard for my A levels when I had been told that I was going to be dead in a year or so. Therefore, I had a more fatalistic attitude and lived for the moment.

53. However, once there was more stability in my life I returned to education in 1998.

54. It was impossible to have a career with such precarious health. I have always had to get plenty of sleep and my health has suffered when I have experienced stress at work; therefore having a high-powered well-paid stressful job has been impossible.

55. Furthermore, the psychology created by a near death experience did not really make you want to aspire to be in the rat-race; rather I focused on more humanistic things and wanted to improve myself rather than strive for financial gains.

56. My health deteriorated to a point where I had to tell my employer about my health conditions, luckily they were OK about it and offered me a zero hours contract, which has been essential for me to earn enough money to try to support my family. It gave me enough flexibility to ensure that my health did not become compromised.

57. Now, I feel lucky to get opportunities. Even though life is difficult, I do not like to be bitter about it. I know that people all around the world have less support, less opportunities and have had their lives destroyed in different and far more serious ways. We have to be grateful for what we do have in life and try and move forwards.

Section 6. Treatment/Care/Support

58. I came across obstacles when accessing dental treatment. I was unable to access dental treatment for years because no one was willing to deal with me as a patient. A private dentist refused to take me on as a patient and I was always at the bottom of the pile as I was considered deadwood. Why would dentists organise special services and spend money on looking after infected victims when we would be dead in a couple of years.

59. I should have been given access to better Hepatitis C treatments rather than having my life ruined by Interferon and Ribavirin. Further, I was never given recombinant Factor VIII until many years after younger haemophiliacs or non-infected haemophiliacs received it.

60. My infected status has impacted upon my general health care and treatment for years. I didn't have a GP until the 2000s. I had a local GP as a child but I moved out of catchment for the GP in the early 1990s, seeing as we lived in a small community I was concerned about word getting around that I was HIV positive so I refused to relocate to a new GP practice in my town. In small communities it doesn't take much for word to get around and the spectre of discrimination to arise. I only started to use a GP in my area once I was much older and attitudes to HIV had begun to change.

61. I didn't have a dentist until the 2000s and I never had an HIV doctor until the 2010s.

62. Support or counselling was entirely non-existent until the 2000s and in reality was not offered properly until last year when the medical professionals realised that I was still suffering with chemical depression. It makes me laugh at just the mere thought that it could be suggested that there was some kind of support in place for us. We were basically left to get on with it. There was nothing; no support, no counselling, no advice, no apologies, no explanation.....and no future.

63. In the 2000s my Haemophilia unit team were always at the end of the telephone but I was never offered counselling or psychological support.
64. Similarly, in the 2010s, my HIV team advised that they were always at the end of the telephone but there was 18 month waiting list for mental health support in the area where I lived.

Section 7. Financial Assistance

65. I have received money from both The Macfarlane Trust and The Skipton Fund. However, the support has been piecemeal and was not enough to prevent us from living in relative poverty, or living from hand to mouth for the majority of the last 25 years; particularly after my father passed away.
66. I received a payment of approximately £20,000.00 when I was a young teenager and a further payment a little later. However, the money seemed pointless as I had been told that I was going to die.
67. I didn't realise until much later that The Macfarlane Trust offered grants and supported people. Unfortunately my mind-set was to try and get on with life and I missed out on applying for lots of grants because I didn't realise how the scheme operated. Whereas, there were some people "*playing the system*" and getting as much as they could, whether it be through nefarious means or not. I started trying to use The Macfarlane Trust more in my late 20s, but by that time it was much harder to obtain grants and there were numerous hoops to jump through.
68. The Macfarlane Trust discriminated, whether intentionally or not, between applicants and the trust was not fit for purpose. Anne Hathaway, who was in charge of The Macfarlane Trust was very sympathetic and I recall that some familiar faces tended to receive a lot more than others. The whole concept of The Macfarlane Trust was flawed and arbitrary; victims needed to know the "*system*" so many people who were in desperate need never received anything. I received my monthly payments and received grants over the years; but nothing major as I remember.
69. This was a bone of contention as you had to prove need, provide quotes and show that the requested product or service could not be sourced elsewhere. The whole system made you

feel like a low-life beggar asking for help; it was totally disempowering and exacerbated the issues about being treated badly by getting infected, then continuing to be treated badly when trying to obtain some basic financial support.

70. The Macfarlane Trust was in a difficult lose-lose position and I think that the trustees knew that the system was unfair but they did not want to make a political statement regarding this because their funding was not guaranteed. I think that they often tried their best; however, they were tied by the restrictions given to them by the Government. They could've been more vocal in trying to solicit more funding or making a point of the schemes not being fit for purpose with the infected communities.

71. The financial support which we have been given has been a disgrace; a pittance. People have lived in poverty and are unable to escape this poverty trap because of their health which becomes a self-perpetuating cycle of misery.

72. One thing which has always angered me was the fact that because I was younger than 18 I only received £20,000.00. If you were over 18 you received £40,000.00 and if you had children the figure rose to £60,000.00. I wondered whether I was inconsequential due to my age and thought that it was unfair that I did not then receive the uplift when I went on to have children.

73. I feel that my financial pressure was alleviated with the new EIBSS payments.

74. I feel disappointed with the community and feel that it is distasteful how people speak about compensation. Compensation will not make people happier; mentally people need to stratify what has happened to them. Compensation will not lift the feelings of the community. Money can make parts of life easier but it will not bring me back what has been taken from my life and it is not going to change what has happened in my life.

Section 8. Other Issues

75. I found I was eroding as an individual and there was no forward path.

76. The previous Inquiries, Archer and Penrose, have been swept under the carpet. Additionally, there was the previous litigation against the US pharmaceutical companies which was a total farce.

77. This is the NOW, the time for this to be resolved once and for all. It is one of the biggest scandals in the UK in the last 50 years. It has destroyed families and has killed thousands of people and yet still, unbelievably, remains widely unknown in the UK after all these years.

78. My mother and I wrote an oral history "*HIV in the family: An oral history of parents, partners and children of those with haemophilia and HIV*". This was 11.5 years ago and she actually feels that things have regressed over the last 11.5 years. Things need to improve.

79. My mother further recalled there being no '*champion*' for haemophiliacs. We were left to rot and were brushed to one side. She feels so grateful that people now want to hear my story.

80. I want closure to a certain level although this is impossible to a greater level. I want culpability in a moral sense and for us to be recognised as a community which has been wronged.

Anonymity, disclosure and redaction

81. I confirm that I do not wish to apply for anonymity and that I understand that this statement will be published and disclosed as part of the Inquiry. I would like 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 S. GREGG

Dated..... 19-12-2018