Witness Name: MCLEAN, Stuart Statement No.: WITN0653001 Exhibits: WITN0653002-027

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF STUART MCLEAN

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

I, Stuart McLean, will say as follows: -

<u>Introduction</u>

1. My name is Stuart McLean. My date of birth and address are known to the Inquiry. I suffer from Ehlers-Danlos Syndrome and was inappropriately treated with Factor VIII concentrates which infected me with HCV and possibly exposed me to vCJD. I intend to speak about my medical treatment since childhood and in particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on me.

How Infected

- In 1971, at the age of 2, I underwent an adenoidectomy there were no complications arising from this procedure, no unusual bleeding and no cause for further concern was raised.
- 2. Nevertheless, from early childhood it was noted that I bruised extremely easily and I recall that in or around 1975 or 1976 (aged around 6 or 7), I fell from a car and was treated at the Royal Derbyshire Hospital for severe swelling to my knee. I was discharged and ordered to rest with icepacks on the swollen area.
- After this incident, I came under the care of Dr Little, a Consultant Paediatrician at the West Kent General Hospital. Dr Little suspected that I suffered from a bleeding disorder (which he felt would explain my history of easy bruising) and referred me to Dr Holman, Consultant Haematologist at Lewisham Hospital, in early 1976 for investigative tests.
- In tests conducted on 5 July 1976, Dr Holman found my plasma, serum and combined plasma and serum results to be normal and also found my agglutination with ADP levels to be normal (WITN0653002). These results clearly indicated that I did not have a clotting factor deficiency.
- 5. Equally, I have been told subsequently that the removal of my adenoids without any notably excessive bleeding was extremely strong evidence that I did not suffer from a bleeding disorder and should have deterred doctors from making such a diagnosis there is no evidence that the circumstances surrounding my adenoidectomy were given any significant consideration by any of the doctors who were debating (and who subsequently debated) whether I had either haemophilia or Von Willebrand's Disease.

- By 4 April 1977, owing to the distance between my home and Lewisham Hospital, Dr Holman proposed to transfer my care to Dr Nalinda Naik, Consultant Haemotologist at the West Kent General Hospital (WITN0653003).
- 7. On the same day, Dr Holman wrote to Dr Naik (WITN0653004) setting out that I had been referred to him following Kaolin Cephalin clotting test time of 54 seconds (as against a standard of 33-45 seconds) but that his tests had been unable to find any significant abnormality.
- 8. In a letter dated 31 August 1977 (WITN0653005), Dr Naik writes to the Oxford Haemophilia Centre ("OHC") and notes that my Factor VIII levels have ranged from 20-49% of normal levels and that my VIII related antigen levels were in the region 20% of the normal range. Dr Naik goes on to say that she suspects I suffer from Von Willebrand's disease, that she has already discussed my circumstances with Dr Matthews (of the OHC) and that she has enclosed a frozen sample of plasma which OHC should test to confirm her findings.
- 9. Dr Charles Rizza responded to Dr Naik on 13 September 1977 (WITN0653006) noting that he had tested the plasma sample and had found Factor VIII related antigen to be 58% that of normal levels with Factor VIII coagulant activity levels at 26% of normal levels. Dr Rizza goes on to say that he does not attach much weight to the coagulant activity levels and suggests that these results could be unreliable as a result of the tests having been carried out on plasma which had been frozen.
- My medical records become slightly hazy around autumn 1977 but it seems that my GP, Dr Naunton Davies was also in contact with OHC and particularly, Dr Matthews. In a letter dated 18 October 1977 (WITN0653007) Dr Matthews notes that he has conducted tests on me GRO-C , that the results GRO-C are completely normal

and that there is no reason to suspect that GRO-C suffer from any form of coagulation disorder.

- 11. I am not sure whether the direct contact with my GP and OHC caused some sort of animosity but in a letter dated 9 November 1977 (WITN0653008), Dr Naik writes to my GP to say that she has again found low Factor VIII levels in tests conducted upon me, that she continues to believe that I suffer from Von Willebrand's disease but that the "King of Clotting" (presumably a reference to either Dr Matthews of the OHC) does not support her diagnosis.
- In this same letter, Dr Naik advises that should I have an episode of excessive bleeding, I should be treated with fresh frozen plasma or cryoprecipitate.
- 13. On 2 September 1978, I fell and injured my knee badly; I was taken to the West Kent General Hospital and treated by Dr Naik with fresh frozen plasma, cryoprecipitate and (against her own advice of November 1977) Factor VIII concentrates; these were administered over three days.
- 14. Shortly after this incident, on 6 September 1978, Dr Naik wrote and referred me to Mr Stossell, Consultant Orthopaedic Surgeon at Preston Hall Hospital (WITN0653009); she writes:-

"This boy was referred to me for a possible haemorrhagic defect by Dr. Naunton-Davies in November 1977. We have carried out extensive tests and even referred him to Oxford Haemophilia Unit for the most up-to-date tests. We have found no evidence of any coagulation defect although he does repeatedly have extensive bruising and muscular haemorrhages.

On the 4th September '78 he came to see me for a possible haemorrhage in the (R) knee joint which took place over the weekend

of 2nd September. I gave him prophylactic treatment with fresh frozen plasma, cryoprecipitate and facto VIII concentrate over three days. At least there was no further continuation of blood loss in that joint. It continued to be painful perhaps because of the blood that had already accumulated. There were no other systemic signs or symptoms.

Since his (R) knee is the only one joint where his haemorrhage has occurred repeatedly, I wonder if it has any orthopaedic relevance..."

- 15. Dr Naik clearly acknowledges in this letter that there was no evidence that I suffered from any clotting disorder and there is no explanation as to why she treated me with clotting agents despite this acknowledgment.
- 16. Worse, Dr Naik treated me with fresh frozen plasma, cryoprecipitate and Factor VIII concentrates; I have no idea (and nor does any other medical professional I have spoken with) why she would treat me with all three products.
- The only reason I can think that I would be treated with all three varieties of blood product is that Dr Naik wanted to see what would happen if she did administer all three. In 1977, Dr Naik had advised Dr Naunton Davies that I should be treated with either fresh frozen plasma or cryoprecipitate and even this ignores the fact that DDAVP had been introduced in 1977 and acknowledged as an effective treatment for Von Willebrand's (which as has been made clear, I did not have).
- 18. It was known from at least 1966 that blood products were capable of (and likely to) transmit hepatic viruses and the thing that I really cannot understand and which causes me such anger is that in 1978, 12 years later, Dr Naik chose to treat me with every blood product she could get her hands on rather than the entirely safe alternative of DDAVP which would have been perfectly suitable had her belief that I suffered from Von Willebrand's Disease been accurate.

- 19. In short, Dr Naik's arrogant belief that her diagnosis of VWD was correct, in spite of the findings of Dr Matthews at the OHC, led to me being wrongly treated with a barrage of clotting agents which infected me with HCV.
- 20. To be absolutely clear, the clotting agents administered to me in September 1978 did nothing to help my knee and this was borne out by the fact that by October 1978, the condition had still not improved and so yet more cryoprecipitate was administered on or around 4 October 1978 (WITN0653010).
- 21. The confusion caused by Dr Naik's refusal to accept that I did not suffer from a clotting factor deficiency continued into 1979 (and beyond as will become evident from the later parts of this statement). In 1979 there was an exchange of correspondence between solicitors acting for GRO-C

 GRO-C

 and Dr Naunton Davies

 (WITN0653011). Dr Naunton Davies sets out that:-

"It is suspected that the blood condition which he suffers is of an intermittent nature and quite unpredictable. This does mean that bleeding could be serious unless he had hospital treatment if he were in a bad phase."

- 22. I do not blame Dr Naunton Davies for this assertion because he is relying on information from Dr Naik but the simple fact is that I would not have bled seriously and I did not have any form of clotting agent deficiency as confirmed by OHC in 1977.
- By May 1980, my care had transferred to Dr Williams, Consultant Haematologist at the West Kent General Hospital. Dr Williams wrote to Dr Naunton Davies on 9 May 1980 (WITN0653012) to say that clotting levels have usually been normal "when they have been done at

Lewisham, Oxford and here during Dr Naik's time." Dr Williams goes on to say that he feels "quite sure [that I have] a mild form of Ehlers-Danlos Syndrome."

- 24. Dr Williams' diagnosis of Ehlers-Danos Syndrome ("EDS") was correct and I was subsequently proven to have EDS type 3. EDS itself is a genetic condition which causes collagen to form in the body improperly and which therefore causes the connective tissues to behave differently to that of people without the condition. Common symptoms include hypermobility and extremely stretchy skin or conversely, extremely fragile skin which breaks or bruises easily.
- 25. Type 3 (or classical) EDS gives common symptoms including joint hypermobility; loose, unstable joints that dislocate easily; stretchy skin; fragile skin that can split easily, especially over the forehead, knees, shins and elbows; smooth, velvety skin that bruises easily; wounds that are slow to heal and leave wide scars and hernias and organ prolapses.
- 26. There is no treatment or cure for EDS, it is simply a case of managing symptoms as and when they arise.
- 27. In 1985, Dr Williams referred me to Dr Grahame, Consultant Rheumatologist at Guys Hospital following three months of extreme pain in my knees. Dr Grahame diagnosed me with Osgood Shlatter disease (extreme growing pains) as well as Marfan's syndrome which is a further genetic condition which is similar in some of its symptoms to EDS but which is characterised by the growth of disproportionately long limbs and an overcrowded mouth. I believe that Dr Grahame's diagnosis was based on my arm span being greater than my height.
- 28. In his diagnosis (WITN0653013) Dr Grahame also notes that I had been issued with a card setting out that I suffered from Von Willebrand's Disease and he queries whether this is an out of date diagnosis. Again, it can be seen that Dr Naik's misdiagnosis and refusal to accept the

- opinion of OHC was still having implications many years after she had stopped caring for me.
- 29. Later, in September 1985, Dr Williams referred my case to Dr Savidge at St Thomas' Hospital (WITN0653014) he notes two points which I find interesting:
 - a) Despite having treated me for five years confident in his assessment that my 'bleeding episodes' were a result of EDS, he resurrects the idea that I may have Von Willebrand's Disease and asks Dr Savidge to investigate. Dr Williams fails to recognise that my bruises were not bleeding episodes but rather bruises as a result of the EDS.
 - b) I was recognised to have episodes of jaundice and, despite knowing that I had received a volley of blood products in 1978, suggests that this may be indicative of a diagnosis of Gilbert's Disease – hepatitis does not appear to have been considered at all.
- 30. On 4 October 1985, the Headmaster of my school, Mr GRO-D a man I looked up to and admired and who knew of my medical difficulties wrote, without my knowledge or consent, to Dr Williams to ask if I was infected with AIDS and whether he needed to take any precautions (WITN0653015). Discovering this letter within my medical records caused me enormous pain and upset and completely changed my opinion of a man who I had had such respect for.
- 31. Mr GRO-D letter seems to have prompted Dr Williams into action because on 24 October 1985, he wrote to my mother to see whether she would like me to be tested for AIDS virus antibody (WITN0653016)
- 32. The same day, Dr Williams responded to Mr GRO-D (WITN0653017) refusing to disclose my particular details but saying that the risk of transmission of AIDS was so remote that it did not justify the treatment of haemophiliac children as "latter-day lepers". Dr Williams did not take

the opportunity to point out that in fact, I was not a haemophiliac and had no diagnosed bleeding disorder.

- 33. I assume that my mother must have responded to Dr Williams with consent for me to be tested for HIV because there is a letter from Dr Williams to her dated 20 November 1985 (WITN0653018) which confirms:-
 - "...Stuart was tested on the 1st November his results show no evidence of infection with the AIDS virus nor with the Hepatitis B virus."
- 34. I was almost 16 at this time and I had no knowledge that I was being tested for any viruses it seems clear from my notes that Dr Williams conducted the HBV test without any formal consent although I cannot rule out the possibility that he and my mother discussed additional tests over the telephone prior to my attendance on 1 November 1985.
- 35. In connection with this incident, I vividly remember being sat with my brothers discussing AIDS and my mother remarking that I didn't have to worry because she had had me tested, I remember being furious with her and Dr Williams for arranging this behind my back.
- 36. Nevertheless, it is clear that at this point, hepatitis had entered Dr Williams' mind as a possible explanation for my episodes of jaundice albeit, despite the risk of NANB hepatitis being well known to haematologists at that time, there was never any discussion with me or my mother about the possibility that I could have contracted it.
- 37. On 7 April 1992, following a check-up after surgery, my GP, Dr Burland wrote to Dr Williams concerned at my reports of episodes of jaundice (WITN0653019). Dr Burland notes that I am generally unwell most of the time.

- 38. Despite recognising clear symptoms of hepatic illness in his response of 29 May 1992 (WITN0653020) such as jaundice, itchy skin and dizziness Dr Williams took no steps to investigate whether I had contracted HCV an obvious step that he should have taken given that haematologists new universally by 1992 that any exposure to factor concentrates prior to 1987 would almost certainly have resulted in HCV infection.
- 39. Dr Williams remained my haematologist until 2004 or 2005. Between 2004 and 2012 I was not under the care of any specific haematologist until I was referred to Dr Evans at the Kent and Canterbury Hospital by my GP. I met with Dr Evans on 20 December 2012 and she took some blood samples to again test my clotting agent levels again, it was confirmed that I do not suffer from a bleeding disorder.
- 40. At a review meeting with Dr Evans on or around 2 January 2013, she raised a concern that she could find no record of me having been tested for blood borne viruses. I told Dr Evans that I believed I had been tested in the mid-1980s for HIV but I didn't know about anything else. Dr Evans took some further blood samples and I agreed for them to be sent off for testing.
- On 23 January 2013 my results came back and proved that I was HCV positive. My diagnosis came 35 years after my infection.
- 42. I am so angry that for 35 years I have been infected with HCV, through much of this time it was believed that the virus was easily transmissible and had I been fixed with the knowledge of the time, I would have been far more careful in both my relationships and my work.
- 43. There is simply no excuse for it having taken 35 years to test me for HCV, every single person who was treated with blood products prior to 1986 should have been contacted, told of the risk that they were at and advised to be tested for blood borne viruses. Instead, Dr Williams left me (knowing full well that any exposure to pre-1986 blood products

would have infected me with HCV at least) and attributed my symptoms to his misdiagnosis of Gilbert's disease coupled with my other conditions.

- Dr Naik infected me but Dr Williams left me in the dark, to die ignorant of the virus that I had been infected with.
- 45. I don't remember much of what was said to me immediately after my diagnosis with HCV as I was in shock but my wife was with me and tells me that we were simply told that I would be referred to a hepatologist. I was not given any information to take away with me, no leaflets explaining the condition or what I could expect and not even a date when I would meet the hepatologist and receive more information.
- 46. Everything I learned about HCV I learned from my own research on the internet. This was terrifying because you are always led to the very worst case scenarios and I read horror story after horror story not only about how I would die from liver cancer but how horrific that death would be and how appalling the treatments for HCV would be if I sought out a cure.
- I was referred to Dr Kosh Argarwal, Consultant Hepatologist at Kings College Hospital and I was examined on 28 June 2013; Dr Argarwal diagnosed me with chronic HCV though noted that there was no sign of significant swelling or scarring to my liver yet. Dr Argarwal recommended that I begin treatment with three drugs, Interferon, Ribavirin and Telaprevir or Boceprevir which he described as the standard triple therapy treatment for HCV genotype 1b (WITN0653021).
- 48. Dr Argarwal went on to tell me that new treatments with less side effects were about to be introduced and since I showed no evidence of significant liver damage, we agreed that I would wait for new treatments to be introduced.

- 49. I did not know at the time but I have subsequently been told that there is a body of opinion which suggests that fibroscans are ineffective on people with EDS. I know that Dr Argarwal is not of this body of opinion but I also know that ultrasounds have shown that I have an enlarged spleen and fatty liver which are indicative symptoms of cirrhosis this does not correspond with my fibroscans which continue to show no significant liver damage. In addition, I also have a finely heterogenous liver which is not shown in the results of any fribroscan I have had.
- 50. I am not sure why Dr Argarwal maintained his faith in my fibroscan results for so long as I recall clearly one occasion when he tried to conduct a fibroscan upon me but gave up halfway through as my results were bouncing around so much that it was clear no accurate measure could be recorded. I have consistently been told that I cannot have a liver biopsy because I have a bleeding disorder (which of course, I do not).
- 51. On 1 December 2015, I went for a check-up with Dr Argarwal and he discussed new, approved treatments for HCV which did not involve taking Interferon. I was particularly worried about taking Interferon because of both my online research which described the side effects as horrific and because I knew that it could damage blood vessels and I worried how this would particularly affect me in light of my EDS diagnosis.
- 52. I asked Dr Argarwal whether he knew how the new treatments might interact with an unlicensed treatment that I was receiving from America for a separate medical condition. Dr Argarwal initially told me that they would not interact and when I asked him for the basis of this assertion, he told me that he had not even checked.
- 53. I remember that I had had to take my 5 year old grandson to the appointment with me and when I told Dr Argarwal that I did not want to be experimented on again, he told me that if I wasn't going to have

treatment for HCV then I could "get out of [his] fucking hospital". He said this to me in front of my grandson.

54. Following the consultation, Dr Argarwal wrote to my GP the same day, albeit the letter was dated 17 January 2016 (WITN0653022) and noted:-

"I met this gentleman today in the context of his consultation around hepatitis C. I am sorry but I did not feel that we have offered him a good consultation today given his frustration and bitterness about his route of infection."

- The assertion that I had not had a good consultation was a significant understatement and I feel completely entitled to be bitter about being infected with a life limiting virus by the NHS on the basis of a misdiagnosis when, even if the misdiagnosis was correct, I could have been treated with a completely safe alternative.
- 56. As matters stand, I have still not undergone any treatment for HCV, I do not know what state my liver is in and I live in constant fear that my liver has been significantly damaged and that I could, at any point, develop liver cancer.
- 57. I have no faith in the NHS; my treatment over the course of the last 40 years has been a comedy of errors which has not been, in the least bit, amusing. I have variously been congratulated on clearing HCV despite having never had treatment (the doctor having assumed that I had been treated), doctors still refuse to accept that I do not have a clotting disorder and I am still spoken to as though there is a distinct possibility that I did not contract HCV from blood products.
- Two of these examples are demonstrated in a letter to my GP from Dr Gayatri Chahkrabarty, an Honorary Consultant at Kings College (WITN0653023) where the Consultant acknowledges that an

assumption had been made that I had been cured and she then goes on to say:-

- "...He does not have faith in the NHS as he thinks he may have acquired the infection when he was an (sic) young child and was given blood products."
- 59. This letter was written by a liver specialist on 20 July 2018 Dr Chahkrabarty knew, or ought to have known, full well that as a recipient of Factor VIII concentrates, I was certainly infected with HCV through them.

Other Infections

- 60. In November 1992, I underwent surgery for a suspected cancer which involved the removal of an organ. I was treated prophylactically with transamic acid and DDAVP.
- Shortly after my operation I bled significantly as a result of a failure on the surgeon's part to properly seal a blood vessel and on 11 November 1992, I was given four units of fresh frozen plasma (WITN0653024). Other than this bleed, I healed well and gave little thought to the procedure in the coming years.
- 62. On 14 February 2013, in dealing with the repercussions of my diagnosis with HCV, Dr Evans wrote to my GP to note arrangements for addressing the HCV infection (WITN0653025) but she concludes the letter by saving:-
 - "...As he had treatment between 1980 and 2000 it is possible that he is at increased risk of new variant CJD. However I think the guidelines for this are changing and he may not be at risk therefore I have not informed him this at present but clearly if he needs any surgical procedure then we will have to consider this. I am awaiting further clarification from the Department of Health on this issue."

- 63. As Dr Evans notes, I was not told that I was at any risk of having been exposed to nvCJD; I assume from the content of this letter (which I received in error as it was mistakenly posted to me rather than my GP) that it was the plasma I received in 1992 which may have led to an exposure as I received no other blood or blood products between 1980 and 2000.
- 64. I recall an appointment shortly after I mistakenly received this letter where I asked Dr Evans why she would withhold this information from me; I believe she said something to the effect that she wanted to see whether I was at risk first.
- 65. I heard nothing about CJD until 2014 when a brief exchange of correspondence (which I am now unable to locate) led to an appointment with GRO-D, a Nurse Consultant at the National Prion Clinic on 16 September 2014.
- 66. At this meeting, I was told that testing for prions was still at an early stage, that the test would not give a reliable result and that further, more reliable testing may come about in the future whereupon I would be contacted. I was also told not to worry because if I developed CJD then I would be dead within 6 months.
- 67. I have not heard from the National Prion Clinic since and despite being terrified at the prospect of this new threat and particularly that I would die within 6 months of developing symptoms, HCV seemed a much more immediate threat which required regular testing and visits to hepatologists. As a result, CJD slipped to the back of my mind over time.
- During the course of preparing for the Infected Blood Inquiry and in listening to the first witnesses to give evidence, CJD was brought back to the fore of my mind and I requested an appointment with Dr Evans. I attended a consultation with her on 10 May 2019.

- 69. At this consultation I expressed my anger at Dr Evans for not talking to me about CJD when she first had the opportunity in 2013. Dr Evans told me that my mental health following the HCV diagnosis was fragile and she thought it best not to trouble me further. This was not Dr Evans decision to make and it shows me clearly that doctors have learnt nothing from the tragedy of infected blood products and that they are still making the same arrogant mistakes they were making in the 1980s about withholding diagnoses of diseases.
- 70. Dr Evans went on to tell me that she had been unable to obtain any batch numbers for any blood products which had been administered to me.
- 71. Dr Evans wrote to me the same day (10 May 2019) to summarise the things we discussed in the consultation (**WITN0653026**). There are three inaccuracies in her account of the consultation which I list below:
 - a) Dr Evans did not give me the diagnosis of HCV; she sent the information to my GP and he informed me therefore she could not possibly have known my mental state at the time;
 - b) Dr Evans suggests that there are some parts of my medical records which I have not attempted to obtain copies of. From the context, I believe Dr Evans is referring to my records from West Kent Hospital which I have indeed obtained copies of.
 - c) Dr Evans notes that I bled excessively during knee surgery; I have never undergone a surgery on my knee and have never had an excessive bleed – my misdiagnosis of VWD came about as a result of bruising from EDS being confused with a bleed.
- 72. I cannot understand how Dr Evans can have established that I am at risk of CJD whilst still being unable to obtain batch numbers for the products that have been administered to me.

- 73. Following this consultation with Dr Evans, I wrote to the UKHCDO to seek details of the products which had been administered to me both in 1978 and in 1992.
- 74. I was told by UKHCDO that they had no information in relation to me whatsoever (I was supplied with a copy of four blank pages of paper). I was told that it seemed that Dr Naik had never notified UKHCDO of products which had been administered to me, I was told that the UKHCDO records were only as good as the information that was given to them by the treating hospital and that it was a breach of protocol for them not to have been informed
- 75. Dr Naik cannot have it both ways she misdiagnosed me with VWD and on the basis of this (mis)diagnosis she should have sent my treatment records to UKHCDO. She didn't. The batch numbers are not contained within the medical records I obtained from the West Kent Hospital.
- 76. Equally, the doctors who treated me in 1992 failed to notify UKHCDO of the plasma I was treated with though I find this omission slightly more understandable as they were clear that I was not a haemophiliac nor was I suffering from VWD.
- 77. Nevertheless, the batch number was not recorded in (or has not remained within) my medical records and it is now impossible to tell definitively whether I was exposed to CJD through the plasma that was administered to me.
- 78. Because there is no record of the plasma that I was treated with, I was not contacted as part of the lookback exercises which were undertaken I simply cannot know whether I am at risk of developing CJD or not.
- 79. I have had no advice and I do not whether I am supposed to inform my dentist and hospitals that I might have been exposed to CJD – I am left in complete limbo.

Consent

80. As I set out in the first section of this statement, I was tested for HIV and HBV without my consent. Whilst it appears that my mother's consent may have been given for HIV testing, it seems to me that Dr Williams tested me for HBV without any such consent, without giving any form of counselling and entirely of his own volition.

Impact

- 81. The mental impact of being infected with HCV has been overwhelming and devastating. Prior to 2013, I generally had good mental health despite dealing with my various medical conditions.
- 82. After my diagnosis, I spiralled into depression; finding out I had HCV hit me like a ton of bricks and I suddenly felt like I had betrayed my wife had I have known I had HCV I would never have married and burdened Karen with me and my condition.
- 83. I felt (and still feel sometimes) worthless and dirty; the stigma of being infected with HCV is enormous. In 2013, I stood on the top of a motorway bridge and moved to the edge. Final thoughts were running through my mind and I thought of my grandson it was this thought that stopped me from jumping but I still regularly have suicidal thoughts.
- 84. I am now dependent on anti-depressants; my moods are erratic and I have bouts of uncontrollable anger this never happened before my diagnosis with HCV.
- 85. I live in a close knit cul-de-sac and my neighbours were my friends.

 One of my neighbours discovered that I had HCV and screamed at me in the street that I was an "infected hepatitis cunt", she called GRO-C

 GRO-C a "blind spastic" and accelerated her car at GRO-C

 GRO-C as she tried to cross the road with GRO-C

- 86. My other neighbours heard my neighbour abusing me and I then had to go round them individually explaining that I had been infected with hepatitis by blood treatments I had received none of my neighbours speak to me now.
- 87. I live in social housing and the cul-de-sac I live on is operated by a housing association in conjunction with the local authority. When I complained to them about the abuse from my neighbour, they issued me with an eviction notice and said that I couldn't have been that bothered about keeping my HCV diagnosis private because I had been on Sky News talking about infected blood.
- 88. I have applied to move to a new house, but the housing association has so far not agreed to let me move.
- 89. Workwise, I have always worked. Until I was 32, I worked for Thames Water rising from a young labourer to a supervisor. After this, I worked for the local authority on the roads for a year and then I moved to Westminster Council and oversaw the replacement of the Victoria Water Main, the biggest civil engineering project for 100 years.
- 90. I then moved to work for a contractor overseeing BT's installation of fibre-optic broadband cables all across the UK.
- 91. After the depression that ensued from my HCV diagnosis, I was signed off work sick and ultimately made redundant; I have not worked since.
- 92. Fatigue (I assume from HCV) has set in since 2013 and this, coupled with my depression has left me unable to work. Being unable to work has added to my depression, I feel like less of a man being unable to financially support my family.
- 93. My wife has been a pillar of support, she is an amazing woman but I feel like I have burdened her with a curse. I do not know what I can do to ease the weight I have brought upon her and this is one cause of my suicidal thoughts, I often think she would be better off without me.

- 94. At the root of it, I feel like I betrayed my wife; that I conned her into marrying me whilst she thought I was healthy and then discovered when it was too late that I had HCV. The only saving grace has been that I haven't infected Karen with hepatitis.
- 95. Betrayal is a word I come back to again and again I feel like I have been betrayed by most of the doctors who have cared for me but particularly Dr Naik and Dr Williams. Dr Naik recklessly threw every filthy blood product she could find into my veins and then Dr Williams left me, knowing that I would have been infected by the products I had he could have tested me in 1989 for HCV; instead, I didn't discover I had the virus until 24 years after this first opportunity.
- 96. By 2017, I had researched some of the history of contaminated blood, I had reviewed my own medical records and I had come to understand that Dr Naik knew what she was doing when she treated me with blood products and the near certainty that she would infect me with hepatitis of one form or another.
- 97. Making this realisation, I went to Kent Police and reported Dr Naik's actions as a crime on 23 July 2017. After making the report, the constable left me and returned with a handwritten note explaining that Kent Police were not going to investigate the matter (WITN0653027).
- 98. When I was told that the police would not investigate, I asked what would happen if I took some of my blood and injected it into a stranger, and I was told that I would be arrested I asked the constable what the difference was between the crime I was reporting and the hypothetical scenario I had just given him and he could not give me an answer.

Treatment/Care/Support

- 99. Because I cannot trust the medical profession any longer and because they still make so many mistakes with my care, I cannot bring myself to undergo treatment for HCV. I am still infected.
- 100. Because the batch numbers of the blood products I have had have been lost, I do not know whether I am considered a risk for public health purposes as a result of exposure to CJD.
- 101. I assume that if I am considered a risk then I will spend the rest of my life being put to the end of the day for medical treatments.
- 102. This will not be a new experience for me; when I received treatment in 1992, I was supposed to undergo surgery in the morning but I was told that there had been a motorway crash which had taken priority and I was left until the end of the day. Since I discovered that I had HCV, I cannot help but wonder whether the surgeon noted that I had had blood products from my records and assumed I had HCV and therefore put me off until the end of the day.
- 103. Since 2013, I have had a couple of counselling sessions provided through the Hepatitis C Trust which was paid for by the Caxton Foundation but every session I had the lady was in shock at what I was telling her and all I got out of her was a nod of the head. I was pouring my heart out to a nodding toy you get in a car window, the counselling did nothing for me.
- I have recently been told that the best place for me to be treated would be at the Priory Clinic but there is simply no prospect of this happening the Priory's fees are likely to be in excess of £6,000 and EIBSS will only make a payment of £900 for psychological support.

Financial Assistance

105. When I was diagnosed with HCV my GP told me about the Skipton Fund and I received a payment of £20,000 from either Skipton or

Caxton. I used a big portion of this money to re-carpet and re-decorate my house because I was terrified that I might have spilled blood at some point and it might infect my family.

- 106. I now receive £28,000 per year from EIBSS.
- 107. I once made an application to Caxton for a new pair of glasses as mine had broken and I needed a pair for driving to and from appointments. I needed the glasses quickly as I wasn't able to drive the long round trip without them. I was told to get multiple quotes and they would be considered and I would receive a decision within (I think) six weeks. I needed the glasses, so I ended up buying them myself and Caxton refused to reimburse me the argument with Caxton escalated to the extent that my MP, Sir Michael Fallon intervened but Caxton still refused to make any payment.
- 108. The other occasion when I made an application to a fund was more recently when I saw a funeral plan being offered by EIBSS. EIBSS recognise me as a stage one infected beneficiary and their initial literature advertised the funeral plan as being available to both stage one and stage two0 beneficiaries.
- 109. When I applied for the plan I was told that there had been a mistake and that the plans were only available to stage two beneficiaries. When I pressed EIBSS they agreed to give me the funeral plan providing that I did not tell anybody. I received the funeral plan though I feel guilty that I am perhaps the only stage one beneficiary to have done so.
- 110. The disparity between the support mechanisms across the UK causes me anger and worry. Firstly, why is the value of your life different depending on whether you are English, Scottish, Welsh or Northern Irish? And why is your life worth so much less if you are British rather than Irish?

111. Secondly, if I was Scottish, I would at least have the security of knowing that my wife would receive 75% of my support payments after I died, I would know that she would at least have some provision made for her. Because I am English, my wife does not have that security and I do not have that peace of mind.

Other Issues

- 112. I believe that this Inquiry should recommend that compensation be paid to victims at a level equal to that which would be awarded in a civil claim.
- 113. I hope that this Inquiry will find those responsible within government and the civil service and I hope that this Inquiry will recommend that they be held to account, in criminal courts where necessary.
- 114. I have effectively been murdered by Dr Naik, I'm just waiting to die and her crime will be complete.

Statement of Truth

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

