**INFECTED BLOOD INQUIRY**

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**FIRST WRITTEN STATEMENT OF ANDREW MICHAEL MARCH**

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I, Andrew Michael March, will say as follows:-

## Section 1. Introduction

1. My name is Andrew Michael March. My date of birth is GRO-C 1973. I live at GRO-C GRO-C. I have an older brother and a younger sister. I am a composer. I studied composition at the Royal College of Music from 1992-1996 and I graduated with a BMus (Hons) degree.

2. As a result of being treated with contaminated a blood product, Factor VIII concentrate (FVIII), I was infected with a combination of the Hepatitis B Virus (HBV), the Hepatitis C Virus (HCV) and the Human Immune Deficiency Virus (HIV).

3. This witness statement has been prepared with the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are referred to in the body of this statement.

## Section 2. How Infected

4. I have severe Haemophilia A. My FVIII level is very low. I have less than 1 unit per decilitre of blood. There has been no prior family history of haemophilia so it was a complete surprise to my parents when I was diagnosed in 1974 at the age of 13 months. My parents

suspected something was wrong when I kept bruising easily from light knocks and bangs, the kind that were typical of any child growing up.

5. Throughout the majority of my life I have been treated with a wide range of blood products. I started with cryoprecipitate from 1974 – August 1977. Then I received my first FVIII concentrate which was manufactured by the NHS, Lister. On 3rd April 1979, as far as I can determine, I received my very first commercial blood product called "Factorate", manufactured by an American pharmaceuticals company.

6. The batch was R98806. I then received Lister FVIII again, until another commercial product, Kryobulin (made by Immuno) in October 1079. This batch number was 091712078.

7. From about 1980, I also received factor VIII from BPL Elstree, Profilate made by Abbott, Koate made by Cutter Laboratories, Oxford FVIII, BPL's 8SM. Throughout the 1980s whilst I was being given largely, NHS-manufactured Lister/BPL concentrate, there were intermittent doses of commercial Armour Factorate, and this continued right up until February 1988. These Armour doses included two batches which commenced with letter A and a letter B – which, as far as I understand from what I have read, should have been part of an international recall. The suspect batches were: A61190 and B59204.

8. From about August 1995, I received a product called Replenate made by BPL, then as part of a trial, Kogenate made by Bayer. I believe that once I had been put on this recombinant product, I should not have been transferred back to plasma-derived Replenate, but they (The Royal Free) did, and I maintain that this was unethical. From around 2000, I was given Helixate NexGen made by Aventis Behring. I transferred to St Thomas' Hospital, London on 25th February 2005 whilst still on the Helixate product.

9. Shortly after I was moved to Advate made by Baxter. The Advate product was not altogether effective in treating bleeds, and I was eventually moved onto a human plasma-derived product called Fanhdi which was made by Griffols. In May 2017, they finally sorted out my recurrent bleeding by transferring me to a special long-lasting product called Elocta made by Sobi. This is something of a miracle product as I have not had a single bleed since May 2017.

10. I attended a number of hospitals in the West Midlands area: the George Elliot Hospital, Nuneaton, Birmingham Children's Hospital, Gulson Road Hospital, in Coventry. The main

hospital I was under was Coventry and Warwickshire Hospital, which included Walsgrave Hospital if I needed medical intervention during the night. I attended this hospital, under the care of Professor N. K. Shinton, until I was 18 when I left to study in London. Various doctors, locums, registrars, administered the Factor VIII; it was usually not the Consultant, himself.

11. There is no evidence in my medical notes of me having any kind of hepatitis or jaundice whilst on cryoprecipitate. It was only when introduced to FVIII concentrate that I subsequently developed Hepatitis B. In November 1978, when I was 5, I developed hepatitis (with jaundice). I believe this to have been due to infection with Hepatitis B. My blood test results of 21 November 1978 showed Hepatitis B surface antigen with antibody to the core (but no surface antibody) which according to a medical record is indicative of recently acquired infection. I had been on a run of BPL factor VIII which had batch numbers starting "HL1". The batch I received on 11th November 1978 was BPL batch HL1469. The previous one was in September: HL1460.

12. I know that my medical notes state erroneously that I carried on being infectious in terms of Hepatitis B for many years. This was not the case, there were underlying liver function test abnormalities which had not been attributed to another type of hepatitis – which would have been Non-A Non-B Hepatitis, eventually renamed Hepatitis C.

13. My parents were never made aware of the risks associated with using blood products. HBV, HCV, HIV or AIDS were never mentioned.

14. As a result of being treated with blood products, I was infected with a combination of viruses: Hepatitis B, Hepatitis C, and HIV. I still have the marker (core antigen) for Hepatitis B. There is also the additional impact of the two viruses, HIV and HCV adversely impacting each other's prognosis. I am now RNA negative for Hepatitis C since 1994 after being treated with 9 months of gruesome Interferon therapy, however, my liver is far from well and my liver function tests are still elevated. I was permitted to Skipton Stage 2 in 2009 after my consultant described a cirrhosis diagnosis.

15. I was first tested for HIV (HTLV III) in January 1985. However, my parents received a letter from DR M. D. Williams, Registrar in Haematology, Coventry and Warwickshire Hospital which today may seem a little anachronistic, since it was dated 2nd June 1983. It stated: "*I am sure you are aware of the recent publicity about Acquired Immune Deficiency Syndrome*

*(AIDS) and the possible risk of this occurring in haemophiliacs using Factor VIII concentrate. We would like to monitor all our haemophiliacs because of this and would therefore be grateful if you could attend the Blood Bank, Walsgrave on June 30th for a blood test".* A copy of this letter is now shown to me marked **WITN1369002.**

16. This request predates even the AIDS test by nearly two years, so I can only assume that this was some sort of serum collection exercise or perhaps they intended to use some sort of surrogate testing, such as looking at T-lymphocyte abnormalities? That letter was contemporaneous with the dreadful publicity on the TV and the receipt of it at that time had the effect of notifying our family that I was not only at risk, but reading between the lines, it was more likely than not that I had been infected. I believe that when they first knew something was wrong they collected samples for a library so they would be able to test retrospectively when a test was developed (as they no doubt knew it would be).

17. So although I was not officially tested until January 1985, it was very much the case that we suspected it much earlier. Even in January 1985, I do not believe that my parents were clearly and unequivocally told. I don't think they were ever informed by the haemophilia centre, it was left to our family doctor to explain it all and this did not happen until well into 1986.

18. On 1 August 1996, a special medical report was prepared by Consultant Physician, Dr David Hawkins of the Chelsea and Westminster Hospital. Dr Hawkins stated in relation to HTLV-III (HIV), that there was no clear record in the medical notes available to him of my parents being informed. It was also the case that my GP was not informed by my haemophilia centre (Prof. Shinton) of the HTLV-III result of 3rd January 1985 until some 8 months later. A full copy of this report is now shown to me marked **WITN1369003.**

19. There is evidence in my medical notes which shows that I must have developed HCV by 1979 at the latest. However, both my parents and I were completely unaware of this at the time.

20. I was secretly tested for Hepatitis C on 21st January 1991, which was about 2 years after HCV was first described and the blood tests started to become available. I was not aware that this test was being done. The purpose of it was not mentioned to me or my parents. Similarly, I have no recollection of ever being informed by doctors of the significance of my ongoing transaminitis or what was causing it.

21. Prior to October 1992, I had not even heard of Hepatitis C. It was only on my transfer to the Royal Free Hospital after being offered a place to study composition at the Royal College of Music that during an initial consultation at the hospital, that Dr Marion Wood mentioned Hepatitis C and I asked *"What on earth is that?"* I believe that my own medical notes provide strong evidence of non-consensual, undisclosed testing for Hepatitis C as referred to at paragraphs 22 and 24 below. The relevant extracts from my medical records are exhibited at **WITN1369004.**

22. During this induction-style consultation, it suddenly became clear to me that I was infected with some other kind of virus, a new hepatitis virus called "HCV" which was something that I had never heard of before. Dr Wood spent some time attempting to explain it to me and bring me up to speed. She seemed surprised and concerned that my previous hospital clearly knew of my HCV status and test result (since they had recorded it in their transfer (referral) letter of 14th September 1992) but had not told me. The transfer letter was written by Dr GRO-D, Consultant Haematologist at Coventry and Warwickshire Hospital and addressed to Dr Christine Lee. I was not even aware of this letter until 2003 when I acquired my medical notes. Dr GRO-D stated in the letter that: "He is anti HCV positive and has intermittent elevation of liver enzymes."

23. The concern of the Royal Free that I did not know about my diagnosis of HCV was confirmed in a reply letter to Dr GRO-D on 28th October 1992 in which Dr Wood expresses the following: *"On further discussion he did not seem to be aware that he was Hepatitis C antibody positive and we therefore spent some considerable time discussing our understanding of Hepatitis C infection and the implications of antibody positivity."*

24. From my personal perspective, it was on arrival at the Royal Free Hospital in October 1992, that I was informed for the first time of my HCV status. The sequence of events indicates that I had been tested (specifically for HCV - as opposed to NANBH surrogate testing) some considerable time prior to this at Coventry & Warwickshire Hospital, without consent, and without being informed of the result. I believe this was part of a national approach where UK haemophiliacs were surreptitiously and non-consensually tested for Hepatitis C virus from as early as mid-1989.

25. I started to research this area in detail in or about June 2008 following discussions with the late Haydn Lewis. It was he who first piqued my interest in the Advisory Committee on the

Virological Safety of Blood (ACVSB) files. He told me that Westminster had destroyed their copies and that he was trying to get hold of copies of the Destruction Dockets (which he eventually succeeded with). It soon became clear that Scotland had not destroyed their copies and I was able to download 14 volumes from the ScotBlood website.

26. I printed every document in each of the 14 volumes and went through them highlighting anything that interested me and then prepared summaries of each volume.

27. At one point there was a discussion amongst some members of the Tainted Blood community about working towards a publicity stunt whereby the 14 files of documents would be printed out and we would box them up and pose for photographs delivering them to the Department of Health. The story, from our point of view, was that it was claimed Archer was a full review but we had found 14 files of documents which the Government said had been destroyed. This never happened but the point remains true to this day – the Government has never released all the relevant documents – we have been drip fed information and documentation for the last 30 years.

28. From my research I know that ACVSB knew about the new Chiron HCV test from at least as early as May 1989 (if not earlier). The US patient for Chiron's HCV assay was filed as early as November 1987 and the research went back to 1982. By July 1989 a specific request was made for data on Haemophiliacs to go to Dr A. Rejman (DHSS Haematologist). The nature of this data would have been in relation to Hepatitis C infection rates. This is supported in the minutes of the HCDO meeting in October 1989 where there is a willingness to accept samples for Hepatitis C (HCV) testing and by November 1989 it is clear that the ACVSB committee members and the Department of Health were aware that as many as 70-80% of haemophiliacs were positive for Hepatitis C.

29. The really disturbing part of these developments is that all of this was going on behind the scenes during the HIV Haemophilia Civil Litigation. The vast majority of the haemophiliacs who they were garnering these samples from and secretively testing for HCV were at the same time litigants in the HIV Haemophilic case. It is clear to me now that the testing of UK haemophiliacs for HCV was enacted over 1 year prior to the alleged 'waivers of undertaking'. The government were unlawfully gauging and trying to limit their liability for Hepatitis C whilst we were already before the courts on the matter of HIV. At the bare minimum, this is an example of material non-disclosure by the (then) Defence, and worst, Non-feasance and Misfeasance in Public Office.

30. I wrote to the then Minister, Ann Milton, at the Department of Health on 5th November 2010 regarding various issues in the wake of the successful 2010 Judicial Review. In particular, I highlighted the sequence of events surrounding the emergence of the Hepatitis C test and the apparently unethical manner in which many haemophiliacs (most of us?) were non-consensually tested for Hepatitis C and then not told the results for several years. A copy of this letter is now shown to me marked **WITN1369005.**

31. I made it clear that prior to the Haemophilia HIV Litigation of 1990/91, the then Government clearly had unique and private knowledge of the degree to which HCV was infecting the haemophilia community and that this knowledge had come to them via the high-powered committee, the ACVSB the responsibility of whom it was to directly advise Ministers. I went on to make the point that the testing of UK haemophiliacs for HCV was enacted over 1 year before the 'waivers of undertaking' emerged. I concluded my comments by making a very strong claim that the examples outlined in my letter represented material non-disclosure and serious deception on behalf of the then Defence (the Department of Health) and that this occurred whilst in litigation.

## Section 3. Other Infections

32. I was tested for Hepatitis E at some point just before 2nd April 2013. The result was described as "*IgG detected, IgM negative.*" As far as I understand this, when IgG antibodies are detected, it indicates that one has had HEV at some point in the past.

33. I was also exposed to vCJD between December 1995 and August 1997. This involved being treated with 110 vials of BPL Elstree's Factor VIII called "Replenate". These vials were comprised of 2 batches, which were subsequently deemed to be "implicated" for vCJD and are recorded as being "High Risk" in the Health Protection Agency recall tables of September 2004. The implicated batch numbers that I had injected were: FHE4437 (Released 21.09.95; Administered 08.12.95) and FHF4625 (Released 29.07.97; Administered 08.08.97). Being designated "At Risk" of vCJD for Public Health Purposes has caused me great distress – and I know I am not alone in this. I have relentlessly pursued this subject, researching wherever possible, and writing to the Government and various scientists. I have a great deal of paperwork and correspondence on this subject.

34. In July 2009, I commenced a legal action over exposure to vCJD but the case could not progress beyond the most embryonic stage. There is now shown to me marked **WITN1369006** a copy of the summary prepared by Michelmores in relation to this case for the Legal Services Commission.

35. I wrote to the vCJD Trust asking about the position of haemophiliacs. I made contact with Dr Stephen Dealler who was most helpful. I wrote to Dr Gascoign at BPL to find out more information about the batches I had been given. I have relentlessly pursued access to the prototype vCJD blood test – to no avail. I became so concerned about vCJD exposure that I, and another haemophiliac friend, sought a referral to Professor John Collinge, Professor of Neurology, at the MRC Prion Unit at UCL. I was accepted as a patient. This turned out to be a beneficial experience, although it saddened me, as it was like suddenly being given private healthcare and showed up the gross inadequacies, lack of good honest care, almost poverty-stricken approach of haemophilia care in the UK. I provided much-sought after blood as an exposed haemophiliac in order to help with their research. I did this several times. I was eventually given a special genetic test to determine my genotype in relation to vCJD, and was found to be "V-V" (that is valine homozygosity at Codon 129 of the PRNP Human Prion Protein Gene).

36. I recently watched the vCJD documentary on BBC2 "*Mad Cow Disease: The Great British Beef Scandal*". I was pleased to see Dr Dealler speaking on the subject following the correspondence that I have had with him in the past.

37. I know the documentary did not mention the exposure of 4,800+ persons with bleeding disorders but it was still an excellent documentary. I very much felt there could be a "Part II". I note that the Haemophilia Society posted comment on their website following the documentary stating "we are seeking advice on what this means for our community, and we will share any information with you as soon as possible." That was on 12 July and no further information has been forthcoming.

38. I only sought a referral to the National Prion Clinic to get some answers which, until then, had been severely lacking. I was living in abject fear until I became a patient of Professor Collinge. I really do think he is a remarkable man and always had time for me, no pressure, no rush; this was in stark contrast to some of the other experiences I have had over the years with medical professionals.

39. I acquired some additional medical notes some months ago from the Prion Clinic (UCL). However, after reading through them, I couldn't find anything in there about being tested for my vCJD genotype. I know that I most definitely was, and I know that I am a "V-V", as set out above. I was disappointed that they had either taken this info out, or not recorded it in the first place. I don't mind too much, because I can remember the lengths Prof. Collinge went to explain things to me.

40. For example, Professor Collinge said that I was very special because I had the V-V genotype (homozygosity at Codon 129 of the Human Prion Protein Gene - PRNP). He explained that all mammals were M-Ms. He explained that the vast majority of vCJD cases were in humans who also had the M-M genotype, but that there had been one definite human case of an M-V genotype (which we heard about in the BBC documentary). He told me the breakdown of the three genotypes across the population: which were approximately 42% M-M, 46% M-V, and 12% V-V. Prof Collinge said that I was in the V-V group of a rare 12% of the population. He said that I had my parents to thank, as each of them must've had a "V" to give me, for me to have two sitting on Codon 129.

41. I naturally wanted to know whether this was good or bad, for me? He said that the V-V group would most likely have the longest of the possible incubation periods across the three genotypes, but that there was more to it than that. He explained that the M-V and V-V genotypes were polymorphisms unique to human beings (mammals, including bovines being M-Ms), and that they had been able to alter mice by giving them human characteristics, transgenically altered, so that there were in fact mice with the V-V genotype. He said that even when they inject vCJD (abnormal or misfolded prions) directly into said 'altered' mouse, that even at high levels, the scientists have found it hard to get the vCJD infection to take. He went on to tell me that I was very special and that even with the significant exposure to vCJD-implicated factor concentrates which I had had, that he truly believed that I would not succumb to vCJD due to my special genotype. I was now even keener to provide my special blood for research, and my offer was enthusiastically taken up!

42. I have benefited immensely from this knowledge, more than words can say. As a composer, to have received this reassurance, and to have my fears assuaged, not least because I need my mind to be able to write music, well it was the most wonderful news I could ever have been told, and there has not been much good news over the years. I know

the science is embryonic, and that there's a danger of being too literal about these things, but I will keep an open mind, but seize hold of this information positively for the time being.

**Section 4. Consent.**

43. I categorially believe that I was tested for Hepatitis C without my consent or knowledge, and without my parents' consent or knowledge. Similarly, the positive result was not made known to me for at least 21 months. This is supported by Dr Hawkins' Medical Report, where he states at pages 3 to 4: *"There is no record that Mr March was told that he had Non A, Non B Hepatitis or Hepatitis C until he transferred his care to the Royal Free Hospital in London..."; ... "Antibodies to Hepatitis C were subsequently detected on 21 January 1991, but there is no evidence of this information being converyed to Mr March or his parents until he was told by Dr Christine Lee on 28 October 1992, where it is stated in her notes that the patient was not previously aware of this diagnosis...".* The effect of this is that I was entirely unaware that there was an ongoing problem with my liver, and neither my parents nor I were given any advice on cross-infection, etc. This was totally unacceptable.

44. I also believe that my parents were not informed of my HIV status after I was tested in January 1985. This is confirmed on page 3 of Dr Hawkins' Medical Report: *"Mr March's blood was first tested for HIV (HTLV III) in January 1985 which is reasonably soon after the test started to become available in the latter part of 1984. There is no clear record in the notes available to me of the parents being informed of this, but there is a letter from Dr Shinton, Consultant Haematologist, to the General Practitioner, Dr* GRO-D *dated 19 August 1985 stating "LFTs showed a raised level of transaminitis in 1980, and he has an antibody to Hepatitis B. The HTLV III antibody was also positive six months ago."*

45. Dr Hawkins goes on to say: *"Notwithstanding, there was some delay in communicating this information to Mr March or his parents and the GP was only informed some eight months after the test was performed (Letter, 19 August 1995)."*

46. When the doctors decided to switch me from the "safer" cryoprecipitate to pooled Factor VIII concentrate at some point between 10th August 1977 and 10th November 1977, my parents were not asked whether they wanted me to be transferred and the risks were never explained to them. I have asked my parents specifically regarding this question, and they are quite certain that they were not asked for consent to change me from cryoprecipitate to

pooled concentrate, nor were there any discussions of the pros and cons, or risk/benefit balance of the switch-over, and the risks of pooled concentrates were not mentioned at all. In November 1978, I developed acute HBV at the age of five years. Dr Hawkins unequivocally pinpoints the changeover from cryoprecipitate to Factor VIII concentrate as the cause of this: *"There is no evidence that Mr March developed hepatitis in 1976/7 when the sole treatment he had been given was cryoprecipitate, but subsequently he developed Hepatitis B within a year of commencing factor VIII concentrate preparations, which are noted in the schedule. These are likely, therefore, to have been the source of the infections."*

47. Whilst I don't have clear evidence that I, personally, was used in any kind of research, I have done a lot of reading on this subject, and I firmly believe that in relation to AIDS, the haemophiliac community were lined up as a high-risk research group from 1983, as were their wives and partners. I have read about the AIDS epidemic lagging some 3 years behind that of the USA. Instead of using those 3 years to take preventive action; such as looking for safer treatment options, the Government and MRC Scientists saw fit to line up their cross-hairs on the haemophiliac community and make absolutely sure that we were in the path of the infective products destined to come over from the USA to what they termed: "the virgin soil of the UK". I believe with all my heart that this is what they did. I made an FOI to the MRC last year to obtain a clearer, more legible copy of the minutes of the MRC Working Party on AIDS meeting of October 1983, which they kindly sent. So in the context of the above, I have indeed, been used for AIDS research, and I should stress that I was only 9 years old in October 1983. A copy of the minutes of that meeting are exhibited at **WITN1369007.**

48. There was another research aspect which has directly impacted me. It concerns my exposure to vCJD. In 2007 I stumbled across a transcript of America's Food and Drug Administration's TSE Advisory Committee, where they were discussing the testing of blood for new variant CJD. The meeting was attended by a leading member of Britain's National Institute for Biological Standards Control, Dr Phil Minor.

49. Dr Phil Minor (NIBSC) made the following incredible comments during the FDA TSEAC meeting on 19 September 2006: *"Clearly, what you would really like is to have a test which works on humans which you validate on humans. The difficulty with doing that is that there are no human samples available which will do what you want them to do. The best way of doing this clearly would be to take a human, expose them to variant CJD and then follow*

*what happens to them. It is very, very difficult to actually get samples which are relevant to that kind of set up."*

50. *"Finally, we have some samples from hemophiliacs. This turns up just as a bit of serendipity, if you like. There was a study done at the Royal Free Hospital in London over the period of the late 1970s to the late 1990s. Samples were taken from hemophiliacs over the whole of that period, mainly to look at things like hepatitis seroconversions and HIV seroconversions. So, a lot of these things would actually be HIV and hepatitis C positive. Clearly, this is a period of great interest from the point of view of variant CJD as well."*

51. Making this discovery caused me a lot of anxiety. It was like it was happening all over again - a direct repeat of the past attitude to non-consensual testing. I was clearly their exclusive property and my tissue and blood samples were their property as well. I had recently been a patient at the Royal Free. I had been a patient there from 1992-2005. This would affect me directly. I did not want my blood being used for this "mad cow" analysis research without my consent.

52. I was staying with my Haemophiliac friend, the late Haydn Lewis, in Cardiff when we made the discovery. We quickly realised we needed to put a spanner in the works. All of this resulted in an exposé by Ned Temko of the Observer on Sunday 3rd June 2007. The scoop was aptly entitled: *"Patients' fury over blood test 'betrayal'.* The article bore the subtitled: "*Doctors at NHS hospital carry out 'mad cow' analysis without permission".*

53. In a letter of 3rd April 2008, Professor Edward Tuddenham, Director of the Royal Free Haemophilia Centre wrote to me confirming that they did have my samples: *"It is the case that we have samples of your blood stored here, in the form of frozen plasma from various dates between 1992 and 2002. These have not been sent out to anyone for any testing. As came out in the Press, I had been in discussion with Dr Phil Minor to find out if there was interest. However, as we pointed out in the letter to all our patients, no steps in that direction would be taken without consulting with individual patients as to their preference."; "I would assure you that we are, certainly, not going to send your samples to anyone or carry out any further testing on the without your knowledge and agreement."*

## Section 5. Impact

54. It is difficult for me to speak about my HIV infection. I have had it for so long and I am still afraid to confront it. I have not read as much of the scientific literature on HIV. It is far easier for me to talk about other people's situations and my campaigning.

55. I have developed a number of additional health burdens due to being infected with contaminated blood products. Cirrhosis of the liver due to having been infected with HCV, even though I cleared the virus in 1994; splenomegaly, due to liver complications, in November 2017, I was diagnosed with mild ulcerative colitis after colonoscopy which could be due to HIV (there was a question mark over whether it was in fact CMV colitis, or simply Ulcerative Colitis linked to HIV.) In the Autumn of 2018, I was diagnosed with portal hypertensive gastropathy following endoscopy. It is my understanding that it is the harbinger of portal hypertension which causes oesophageal varices. I believe this is as a direct result of the effects of hepatitis C on my liver and thus a knock on effect on my other organs.

56. There is a question over whether my treatment with Roche's Alpha Interferon somehow contributed to my asthma, in particular, whether it made it worse. The medical report of Dr David Hawkins suggests that there may be a link.

57. I've been living with a death-sentence hanging over me since I was about 9 and half years old. I don't think the infection with HIV was confirmed until mid-1985. When my parents were first informed that I had been infected with HTLV-III, they were insensitively told that I would only live for 2 more years.

58. As a family, it was a massive burden and it was not until at least the year 2000 that my parents started to want to be more open about what had happened. For me, it was like having the plague. It was slightly later when I felt that I wanted to reveal to people how haemophilia and HIV had affected my life. In many respects, the stigma and fear surrounding HIV and AIDS have been much more difficult to cope with than the virus itself. As a result, I lived for many years in abject fear of people finding out my status, and even disclosing that I am a person with haemophilia was too much of a risk in case someone put two and two together and figured out that I was more than likely to have contracted HIV. Even now, it is an act of bravery for me to openly tell my story.

59. Sometimes it seems as though a never-ending list of pathogens and viral agents keep popping up. I was notified in 2001 that I had been exposed to vCJD. The doctors had said "theoretical risk...", as if that was somehow supposed to mitigate the horrendous news. There was not yet a widely-available test with any degree of reliability. The Health Service should have learnt its lesson long ago. This was the third wave, or third scourge. There was no excuse. I was informed that two of the batches of BPL's Factor VIII blood product, "Replenate" may have been contaminated with vCJD. It wasn't like I could go and have a test done; it was awful to have yet another fear of a virus hanging over you. The extent of my concern was recorded in a letter of 29 July 2009 to my then GP, Dr GRO-D from Dr David Bevan, Consultant Haematologist and (then) Director of St Thomas' Haemophilia Reference Centre: *"Andrew remains concerned about his vCJD prion status, and I have received a letter from his legal advisor asking me to proceed to blood testing for pathogenic prions..."*

60. I wasn't aware that this virus could still remain active after the heat-treatment process. This contamination would not have affected me if the NHS had switched the medicine of all adult haemophiliacs when they actually knew that blood-borne viruses were still a problem (c. 1991). They delayed farming-out the genetically-engineered Factor VIII called 'recombinant' for adults in England, on cost grounds. I was not exposed until December 1995. I fully believe that the exposure of more than 4,000 persons with bleeding disorders to batches of clotting factors that were subsequently deemed to be implicated for vCJD could have been avoided. This is not solely due to the failure to switch patients to recombinant products, but because a Government doctor, Hilary Pickles, Principle Medical Officer (PMO) for the Department of Health, knew on 2nd February 1991 that prions could be a problem for blood products used to treat haemophiliacs. She recorded in her submission paper to the ACVSB that *"viral inactivation procedures were unlikely to be adequate to deal with the CJD agent".* Despite this awareness, Government advisors ignored the risk of abnormal prions in blood products and the infective vCJD agent was allowed to reach over 4,000 patients. I am one of them. I have lived in fear of this ever since.

61. In terms of the educational impact, I was still at middle school GRO-D in Nuneaton when there were special reports and adverts on the television with the terrifying imagery of falling gravestones and icebergs; there was complete public hysteria which I believe was wrongfully precipitated and whipped up by the Government. As a consequence, I was treated terribly at school. My parents, along with a haemophilia liaison nurse, were required to go to a meeting with an over-reacting headmaster and teachers; to

explain that other pupils couldn't catch AIDS from just being near me or from physical contact. Incidents such as this caused my adolescence to be a very traumatic time. Being told that you had some virus in your blood that you were going to die from completely messed up everything that you thought you knew up until that point. I'd bravely told a trusted school-friend about my HIV status, and he had totally panicked and decided that he would feel better if he could graffiti a prominent wall on route to my school with ill-informed and phobic material. It made me feel like a leper.

62. At the approximate age of 14, I was not coping well. There was no counselling available back then. My adolescence was a traumatic and delicate time. I had been told by my GP, rather insensitively, that I would not live to see my 18th birthday. I had been crying a lot and whilst outside, I looked straight up at the sky questioningly, asking "Why is this happening to me?" I went to school as usual, but on the way, I bought a whole bottle of Aspirin. I knew very well that haemophiliacs were not to take Aspirin because it causes haemorrhaging. In a state of complete despair, I took the whole bottle at once; this was because I didn't want to live any longer as an outcast with HIV. I proceeded to school as per usual, where later that day I became extremely ill, vomiting large quantities of blood. It was frightening and only made things worse because I ended up in on a ward in a hospital with gastric haemorrhaging. My GP at the time, who had been more than instrumental in leading me to that terrible place, visited me in hospital and never twigged that it was an overdose or that it might have been anything to do with his handling of my status. I never told him. He was happy to believe it was simply a case of gastric haemorrhaging from some sharp-edged crisps I had eaten! To add insult to injury, there was a prominent sign above my bed with yellow and red writing, stating: "BIOHAZARD - Danger of Infection". On seeing this I was initially horrified, but then I had a moment of calm acceptance as I realised that there would be no easy escape for me. I don't think there was meant to be.

63. I left school at 16 and went on to do A-levels at college. After that I secured a place at the Royal College of Music in 1992 to study composition.

64. At some point during my degree at the Royal College of Music, there was a major dip in my health – brought on by the pressure and expectation. My immune system plummeted and I became borderline AIDS or ARC (Aids Related Complex). I developed thrush of the oesophagus and shingles. A strange fungus appeared on my head, and there were repeated, unrelenting chest infections that required copious amounts of antibiotics. My CD4 count went down to 150 and my viral load was in the many tens of thousands. I was

so close having to take antiretroviral combination therapy for the rest of my life. I thought that it would be the beginning of the end for me. My doctors said, "*I thought you knew that your immune system would eventually become depleted and your HIV would turn to full blown AIDS? I thought you realised this?*" Obviously, I hadn't taken it in at all. But then who would in those circumstances? Even then, I believed that I could get better; I just knew somehow it was possible – so my Mum prayed for me with a friend of hers. I did eventually recover from this dreadful trough and miraculously, this was without the help of the combination therapies.

65. I graduated from the Royal College of Music in 1996 and, around that time, Professor Lee said to me "you know you haven't got very long to live – spend your money, do and see what you can." She then plotted a graph for me relating to my immune system which frankly looked like the Wall Street crash.

66. My infections have held me back all the way through my career. I know that my haemophilia has also held me back to some extent but I believe that I would have had and been able to accept more opportunities if I had not contracted my various infections as a result of treatment with contaminated blood products.

67. I was affected by the subtle messages being given to me on the medical side. I was constantly faced with doctors telling me what they thought my life expectancy would be. The deadlines they gave me were like pylons on the landscape of my life and they would loom before me.

68. In 1998 my composition won first prize in the Masterprize International Composing Competition. After that there was a media frenzy. I was on CNN and appeared in international press from Switzerland to China. I was thrust into the public eye and was absolutely terrified that someone would find out that I had HIV. At that time I was given a cluster of business cards from recording companies including EMI but I didn't feel able to discuss any of these opportunities and, in the end, they just slipped by because I was too afraid to follow them up.

69. I had an inkling of what it would be like to be in the public eye and the complete terror at the possibility of my HIV status being revealed.

70. I found it particularly difficult in 2004/5 when I became more public about my HIV infection. There was a media surge at that time and I was somewhat swept away in it.

71. The stigma associated with HIV in particular is terrible and, to some extent, continues to this day.

72. Looking back now, I have utter contempt for the medical profession and Government over their mishandling of the AIDS crisis. This suicide attempt was caused by the medical profession prescribing what I can only term as a "death-date". It showed a complete lack of faith in anything other than brutalist science and was borne out of the maleficence of blanket diagnosis. Perhaps if they'd considered me as a unique individual, they might've understood that my body's response to HIV would be my own. It was particularly pernicious to keep prescribing their thoughts on my possible life expectancy. Most physicians I have come across seem to be awfully good at overlooking the apocryphal; like a person's positivity, the spiritual will to live, as well as the benefit of an appetite that could eat for whole of England.

73. I hope that these catastrophic events that I have lived through as a haemophiliac will somehow become a synthesis with my composing so that at least in my music it can all mean something good.

**Section 6. Treatment/Care/Support**

74. I would like to state that I believe the length of time between being infected with Non-A Non-B Hepatitis/HCV and being treated with Alpha Interferon has had a detrimental effect on my liver and that this is often overlooked or not afforded any credence by hepatologists and treating physicians. Dr Hawkins, in his medical report, states: *"Despite the above, Mr March had evidence of persisting liver inflammation "transaminitis" in October 1979 and this has persisted in a pattern of abnormal and occasionally normal tests over the subsequent years, which is typical of Hepatitis C. In my view, therefore, he probably acquired Hepatitis C around the same time as he acquired Hepatitis B or very soon thereafter and must have been infected by October 1979. The diagnosis was only confirmed with an anti HCV test on 21 January 1991, which was some two years after Hepatitis was described and diagnostic tests started to be developed..."*

75. I believe it is reasonable to take the year of my infection with Non-A Non-B Hepatitis/HCV as being 1979. This would mean that as many as 15 years elapsed whilst the virus went untreated, with untold damage being done. In the 1980s, the Department of Health was in no hurry whatsoever to mandate antiviral treatment of hepatitis C, despite Alpha Interferon

being isolated by Roche in 1980. Since it was originally intended as a cancer therapy, it was not licenced in the UK for use in treating Hepatitis C until c. 1990. I, therefore, argue that there was a delay by the Government to licence Alpha Interferon for use in Hepatitis C and to implement antiviral treatment for Hepatitis C infection and that this impacted on me by leaving my liver to suffer damage from Hepatitis C for up to 15 years.

## Section 7. Financial Assistance

76. Contrary to the commonly-held misconception, there has never been any compensation, and certainly not restitution. In the early 1990s, I received a £21,500 one-off capital payment in respect of the HIV Litigation. In addition I believe there was a £20,000 one-off capital payment. The haemophiliacs, especially the healthier ones, were put under considerable moral pressure to accept this pitiful amount, being told that we should all accept it as time was of the essence because some of the haemophiliacs were very sick with AIDS and could easily not live to see the end of the trial. I wasn't even 18 years old. I now believe that the basis on which the amount was calculated was a mere 3-year life expectancy.

77. The worst part was the way the threat of the so-called waivers (termed "Deed of Undertaking" by the Department of Health) was used in order to coerce sick and dying haemophiliacs into accepting the derisory one-off amounts. I have no recollection of ever signing such a waiver. I would have been under the age of 18 at the time and I have also asked my parents about this and they do not recall ever signing one. The alleged waiver was said to indemnify the government against further legal action, but in reality it would have the effect of preventing haemophiliacs from taking any future legal action, particularly if they were to discover that they had been infected with another blood-borne virus. The timing of this waiver was somewhat propitious for the Government since it turns out to be after the cloning and sequencing of Hepatitis C by the Chiron Corporation in 1987, and prototype tests were already in use prior to 3rd July 1989. Further testing of stored haemophiliac sera was being advocated by the ACVSB at this point: *"The Chiron test had been used in first time recipients of Factor 8Y. Preliminary results had shown no positives, while most recipients of earlier concentrates were Chiron positive. Further study of stored haemophiliac sera was advocated."*

78. The uncanny timing of this is simply too close for comfort as I believe that the then government knew during the HIV Haemophilia Litigation that the majority of multiply-

transfused haemophiliacs also had HCV and that Government were trying to exclude our rights to legal remedies for something they already knew we had.

79. On 9 July 2006, I wrote to the then Secretary of State for Health, Patricia Hewitt MP, to ask if they could locate my signed 'waiver' of undertaking not to seek legal action regarding HIV and other pathogens from contaminated blood products. I stated that I have no recollection of signing such a document and that if I had, I would have been under the age of 18 at the time. I pointed out that the 'waiver' may have been signed by my parents (Mr Richard March and/or Mrs Gloria March), as I had not reached my 18th birthday at the time of the Macfarlane Trust Special Payment 2 (MFTSP2) in 1991. A copy of this letter is exhibited at **WITN1369008.**

80. I received a reply from Bilal Ghafoor of DOH Customer Services writing on behalf of the Secretary of State, dated 17 October 2006: *"We have carried out a search through the Department's files and we have not been able to trace your signed document. We believe that it may have been amongst several files which we know were inadvertently destroyed since that time. We have also approached the Macfarlane Trust for their copy of your waiver. Unfortunately, neither the Macfarlane Trust nor their legal representatives were able to find a copy of your waiver. "* A copy of this letter is exhibited at **WITN1369009.**

81. It is clear from this that the DOH is not able to produce the alleged waiver of 1991, nor do they have any record of the MFTSP2 waiver. They even suggest that the waivers were among the destroyed files.

82. Bilal Ghafoor of DOH Customer Services went on to enclose a blank, unsigned example of a Deed of Undertaking that they claim was signed by other applicants in 1991. This bears little resemblance to an unsigned single-page fragment of what appears to be a waiver from the actual time that I have as a PDF. The example sent by the DOH in 2006 is clearly a modern version typed on a P.C., perhaps intended retrospectively but worded as I would expect them to today. The fragment is clearly a scan of an original typed document where the language used is of its time, for example, the use of the Crown. I was not convinced by this attempt to appease my request by sending a blank example waiver. Copies of both documents are exhibited at **WITN1369010.**

83. I believe that the waiver is now deemed rescinded, or null and void. I do, however, feel conned by the government over this, and what I can only describe as deception and immoral tactics by the Government of the day have done lasting damage to the haemophilia community.

84. There was point where I asked the MFT for a one-off grant as I was struggling with the repayments on credit card debt. I had been to see Martin Harvey, the then Chief Executive, as he had agreed to witness my Will. Whilst I was there, I had asked him if he the MFT would help me with a grant and he said yes. He told me to put the request in writing, and I did. However, when the Trust replied, I was told that they could only offer me a loan, where they would deduct money each month from my regular payments. I reluctantly agreed to this, but I was disappointed as Martin Harvey had led me to believe that the grant would be approved. Looking back, I am very unhappy with the way they handled situations like this as they always had plenty of money. Also, I am fairly certain that they were making illegal loans as they did not have a Consumer Credit Licence at the time, although I cannot prove this categorically.

85. At one stage I sought legal advice in respect of the MFT because I got very cross about the interpretation of "charitable need".

86. If I remember correctly, this initiative started with my friend, who was also a beneficiary of the then MFT. It seemed to me they needed legal advice, so I suggested they use the Law Society's "Find a Solicitor" page, where they could refine a search for Charity Law solicitors. I offered to attend an appointment with them to offer support.

87. The purpose of the meeting was partly to ask whether the means-testing of the support the MFT were offering was lawful but also to examine whether the MFT were still operating according to the provisions of the Trust Deeds, which had been amended many times. We wanted to know whether the charitable need specifically had to be financial. It seems not, form the detailed advice we saw. A copy of the advice received is attached at **WITN1369011.**

## Section 8. Other Issues

### Judicial Review

88. I should mention the successful Judicial Review of 2010, *R (on the application of Andrew Michael March) v Secretary of State for Health* [2010] EWHC 765 (Admin), where I challenged the Government's decision not to implement recommendation 6H of Archer independent inquiry; that victims of contaminated NHS blood products who contracted HIV and hepatitis C should be compensated at a level equivalent to the level at which such victims are compensated in Ireland. The Government's decision was quashed by Mr Justice Holman where he found that the Government's approach to this decision had been and remained infected with error.

### ESA/DWP Issues

89. A couple of weeks ago I received an ESA re-assessment form. This was the very last thing I needed. It arrived in the wake of a 13 month long period of being unwell, which started in July 2018, with a throat / airway problem. I've since had 6 opportunistic rare bugs and 5 courses of antibiotics. I have been passed from pillar to post within the NHS (including attending A&E twice); I have virtually gone insane trying to get this throat/airway issue sorted out.

90. When I received my letter it made me feel suicidal. I started a discussion on Facebook and within a short space of time received over 50 comments from others in the haemophiliac infected community who were also being re-assessed or moved over to PIP. I was also aware of this because my physiotherapist (who I had to ask for a letter in support) said he had received 5 other similar requests. I find it astonishing (and somewhat suspicious) that so many of us have received letters at the same time.

91. I have written to Justin Tomlinson, Minister of State, Minister for the Disabled and a copy of my letter is exhibited at **WITN1369012.**

92. At the point the ESA Work Capability Assessment form arrived, I had just been to my GP and she had authorised an urgent two-week fast-track lung scan. I could have cried. The only thing that might help me in all this, is that due to all the hospital appointments, two visits to A&E in the last year, and over 10 GP visits, and all the test results from the lab, I

will have plenty to add to my long list of medical issues for the form. This is all on top of the problems with haemophilia, arthritis, SVT heart problem, colitis, depressions, anxiety, liver issues including cirrhosis and fatty liver disease, mild erosive oesophagitis, asthma, and more recently early signs of portal hypertensive gastropathy.

93. It's very stressful and not very fair, not least because I haven't been very well. Just knowing I'm being reviewed again is already bringing so much more stress when I already don't feel well and they are still thinking I might have a rare bacterial infection called Stenotrophomonas Maltophilia, which was the 5th bug to come up on a sputum growth culture. The last one, Haemophilus Influenzae, was treated with antibiotics.

94. It only seems like yesterday that I did the last form, and had to go for the physical assessment in July last year.

95. I have now completed the ESA form but it took 6 hours to complete, and I had to do it in 3 sessions, due to not feeling well and also finding it extremely hard to cope with. Towards the end of the form, there was a box asking me about Face-to-Face assessments, and I filled it in, letting them know what I really thought. A copy of this is exhibited at **WITN1369013.**

96. It feels like a witch hunt. I have an incurable infection and I am not going to get better; in fact my health can only deteriorate further from here. I do not understand why I (and others) cannot be passported to avoid the stress of having to go through this process.

97. I believe the Government should at the very least offer a reprieve from benefit assessments for the duration of the Inquiry and I would ask Sir Brian to consider an interim recommendation at this stage along these lines.

98. The Government need to give us a break. And give me a break. They need to let up on this awful persecution. I don't know how much more I can take.

**Other**

99. The main thing I hope for in this Inquiry is for proper connections and correlations to be made following forensic analysis of the documentation. The aftermath of the Penrose

Inquiry was a terrible time. I felt the most horrific deflation. I honestly don't know how I survived it. I was on the phone to my mum from Scotland and I told her that I didn't know how I would survive it. She told me just to get home. I felt suicidal. All the time they (Penrose) took, only to come up with the conclusion that nothing could have been done differently; it was a total lie, denial and cover up. I am reassured that this Inquiry, the Infected Blood Inquiry, will not disappoint me.

100. The scale of this Scandal and the work the Inquiry has to do is unprecedented. I have carried out a lot of investigative work myself (only some of which is covered in this impact statement). At times it has felt like I am looking up at Everest, wondering which snowflake to examine first.

**Anonymity, disclosure and redaction**

101. I do not wish to apply for anonymity. I understand that this statement will be published and disclosed as a part of the Inquiry.

102. I wish to give oral evidence.

**Statement of Truth**

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

Signed GRO-C

Dated 29.08.2019