Witness Name: Stephen Martin-Hanley
Statement No: WITN1376001
Exhibits: WITN1376002-4
Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEPHEN MARTIN-HANLEY

I, STEPHEN MARTIN-HANLEY, will say as follows:-

Section 1. Introduction

1. My name is Stephen Martin-Hanley, DOB GRO-C 1970 and I live at GRO-C GRO-C with my wife.

2. This witness statement has been prepared without 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 set out in the medical chronology at the end of this statement.

3. I have been infected with HIV and Hepatitis C (genotype 3) as a result of receiving infected blood products.

Section 2. How Infected

4. I was diagnosed with Haemophilia A when I was just 9 months old.

5. Initially I received cryoprecipitate from the Birmingham Children's Hospital. As we went there quite often for treatment, my father was usually allowed to administer the treatment to me by himself if it was busy. My first treatment with Factor VIII was on 11 February 1981 for a bleed on the back of my left knee. From then on I was regularly treated with Factor VIII, as shown in the copy of my treatment records attached at **"WITN1376002".**

6. My treating doctors were Dr Hill and Dr Derbyshire. The Ward Sister was Sister Marion.

7. My mother had heard rumours that the Factor VIII treatment was potentially dangerous and therefore didn't want me put on it; however Dr Hill and Sister Marion assured her that the product was completely safe.

8. By 1986, my mother had become aware of the link between haemophiliacs and HIV, so she took me to the hospital to ask if I was at risk. The doctor (who I believe was called Dr Derbyshire) suddenly looked very nervous and went into another room. When he came back he confirmed that I was indeed HIV positive.

9. I was not told too much about the virus, other than it could be spread through needles and sexual intercourse, and that I would have 2 years to live. The doctor mainly emphasised that I should not tell anybody about the disease and that I should be careful of the neighbours finding out.

10. This was extremely difficult when I was growing up as I couldn't even tell my friends or teachers what I was going through or that I would soon be dead.

11. In 2005 my notes were reviewed and I was told that I was infected with HIV prior to 1983 because the earliest HTLV-antibody detected was in a sample from 1983. The relevant letter is now shown to me as **"WITN1376003".** However, as I had not been told about this test or the results of it, if my mum didn't take me to the hospital to ask I do not know when they would have told me about my infection.

12. It was not until 1992 that I was told about my diagnosis of Hepatitis C. Again, I had to go to the hospital and explicitly ask if I had been infected with the disease for them to tell me that I had.

13. In July 1994 I was offered a liver biopsy to assess my suitability for interferon therapy.

14. I was informed that this infection had been caused as a result of the treatment I had received, but they did not give me much information other than that. With pretty much any question I asked about Hepatitis C I was simply told that I would have to 'wait and see'.

Section 3. Other Infections

15. As well as HIV and Hepatitis C, I had also been infected with Hepatitis A. Yet again, this was not something I was ever told about.

16. I have received letters warning me that I may have been exposed to vCJD. I received this in information in late 2004 after my GP received a letter. This is shown to me marked **"WITN1376004".** Since that time I have essentially lived from then with the assumption that I do have the disease as there is not a test for it.

17. It is clear from my medical records that my doctors thought I had lymphoma at one stage. I was not advised of this at the time and was not aware that tests were being done for this until I was given access to my records recently.

18. I also had Epstein Barr and believe I contracted this from the receipt of contaminated blood products.

Section 4. Consent

19. Neither my family nor I were made aware that they were testing me for HIV or Hepatitis (A, B or C). I only became aware that I had ever been tested when I received my diagnosis.

20. I was also tested for Epstein-Barr without my consent.

Section 5. Impact

21. It is important to say that because I was infected as a child I don't really know what it is like to be "normal" (not infected).

22. Whenever I was admitted to the children's hospital in Birmingham I would always be put into the ward of severely ill children. It was tough spending time in hospitals with children dying around me, and I recall on one occasion I ran away from hospital in my pyjamas.

23. Later on when I received dental treatment I remember the dentist coming to treat me in so much protective gear that he looked like Darth Vader. In the early days of my HIV diagnosis even the medical staff at the hospital didn't want to touch me. I was put on a isolation ward and made to feel like a leper.

24. It was incredibly difficult being told that I had 2 years to live when I was just 15 years old. My entire life and mind-set completely changed and I quickly went from being a bright, hardworking student in the top sets to struggling in the bottom sets at school. I no longer had an interest in getting a good education because I thought that I would be dead soon anyway.

25. Most of my life has been spent in a cycle of being told I had 2 years to live, staying alive for that time and being told I had another 2 years to live. This only changed recently when I was told I would probably live past the age of 60.

26. Repeatedly being told I had 2 years to live meant my approach to life was always short term. If I received a lump payment from one of the Trusts or Funds, I would spend it quickly on things such as nice cars as there was no point in trying to save money when I was dying.

27. I note that in my medical records it states I was never persecuted. What the notes do not say is that we were all advised to keep our condition a secret. However, people knew about my haemophilia and therefore even though we had kept my condition a secret, people started to put two and two together.

28. I was bullied through my last few years at school due to the media campaign about HIV, and the link between HIV and haemophilia. This bullying continued into my job with the Birmingham City Council, where I started working in the post-room before working my way up to an administration manager. My 12 years there were difficult as I was ostracised by my colleagues who would make horrible comments whenever I needed time off work when I was unwell. I eventually left the job in 2000 as I became too ill to work.

29. Knowing that I could not tell anyone I had HIV made me shy and withdrawn. It was like being a sheep living in a cage of lions – one wrong move and you're in trouble.

30. I have also never been able to obtain health insurance or a mortgage.

31. The next decade was plagued by aspirations and opportunities that were hampered as a result of my illness.

32. I was approached by Pop Idol US who had heard some of my songs on the internet and offered to fast track me to the live auditions in front of the judges. They wanted to fly me out to America for the auditions however I was unable to enter the USA due to my HIV status.

33. After that, an album I made was added to the ballot for the Grammy Awards in 2008. Again I was unable to go to America due to my illness.

34. Most days I feel tired, sick, dizzy and claustrophobic and have headaches. I have nerve pain, peripheral neurosis, thinning of the bones, groin aches, stomach issues, liver issues, hives and allergies and ulcers. I also suffer from insomnia, yeast infections, severe migraines, bowel cramps and incontinence issues due to possible nerve damage. I still suffer from mental issues and have had sores, ulcers, blisters and candida in my mouth for years. This is extremely painful and makes talking and eating difficult.

35. I have a very weak immune system and have suffered from the Epstein Barr virus as well as suffering from severe tonsillitis for almost 2 years.

36. I haven't eaten properly in about 12 years; I can't eat certain foods or at certain times otherwise I will be ill. I am now allergic to certain foods, animals and plants that I never had a problem with before.

37. The hospital is also monitoring my sleep as my last set of tablets caused me to hit out in my sleep. This meant my wife and I had to sleep in separate rooms.

38. Alongside these physical issues comes the mental anxiety of having to live my life in this way. I feel isolated and alone, and live with the paranoia that everyone is judging me and will turn against me.

39. This paranoia is likely a result of growing up with HIV warnings all over billboards and adverts, government scaremongering and the link between HIV and haemophilia.

40. I also have a fear of doctors having been lied to and mistreated in the past. For my latest course of treatment I needed my doctor to promise me that she was doing this of her own accord and wasn't pushing me onto the treatment because the government told her to.

41. I have felt the stigma surrounding the virus my entire life, from when I was bullied in school to this day. At my last house, I was good friends with my neighbour until she found out that I had been infected with HIV. Everything changed from that moment on, and she soon became hostile towards me and our relationship became toxic. I therefore had to relocate and event went as far as legally changing my name.

42. The stigma is also felt by my family, and my sister recently admitted that she avoids telling her friends about me. I also suffer from the double stigma as not only do I have HIV, I am also on benefits. This just adds to my sense of isolation as people see me as a scrounger as my disability is hidden. In this respect I have also found people to be hostile when they have seen me park in a disabled space.

43. Over the years I have also been reported by neighbours for benefit fraud because, due to the support I have received from various funds, I have been able to afford some additional luxuries even though I have been reliant on benefits. This has made my life very difficult at times and has resulted in me moving on more than one occasion.

44. Being forced to rely on the benefits system creates an additional stigma and I have campaigned for some time to try and ensure that those who have been infected as a result of this scandal can access the financial support from the DWP more easily. It remains my view that those in the co-infected community in particular should be passported to avoided annual reassessments of their condition. We are a small group and our HIV is not going to be cured. We should not have the additional burden of being reassessed for support that is critical to our lives.

45. Over the years I have also been penalised for having additional space in my house. Nearly £2,000 a year of the support money I receive is taken away by the fact I have to pay bedroom tax. I went to Court to try to overturn the decision. The Judge thought that I should be exempt. My Housing Association agree but GRO-C Council still charge me. They have not taken into account the fact that I use the additional space for my treatments.

Section 6. Treatment/Care/Support

46. I have received numerous drugs over the years in an attempt to treat my HIV. I have never really had a problem accessing treatment, which could possibly be due to my frequent meetings with the DWP and MPs.

47. In 2007 I started treatment with Truvada. However, recently everyone was strangely switched off this drug and moved to newer medication. There is currently a large scale group action lawsuit in America against the drug company regarding Truvada. This might be the reason patients in the UK had their drugs suddenly switched.

48. I am currently receiving Tivicay and Descovy. These drugs give me chronic groin aches, tiredness, sickness and chronic insomnia.

49. I went for some counselling when I was first informed of my HIV infection at Birmingham Children's Hospital, however I did not feel comfortable with the counsellor so only went twice.

50. I later had some counselling at the Queen Elizabeth hospital due to my agoraphobia and panic attacks, where the counsellor told me that I was on the verge of having a complete mental breakdown. They often wanted to put me on medication whilst taking other tablets for my treatment, but I would refuse as I was conscious of the amount of drugs they wanted me to take which I don't like doing unless I absolutely need to.

51. There is currently full time psychological support at the Haemophilia Department however I have not used it.

52. Initially my doctors thought my Hepatitis C was curable. For a number of years they tried to badger me into having treatment but I made it clear I did not want to have Interferon and until relatively recently all treatment options involved some Interferon. They then tested the genotype and found that I had Hepatitis C Type 3 which is considered the most difficult to treat.

53. I have been told that my liver is deteriorating and I am due to start a new treatment after Christmas to see whether it can clear the virus.

54. Even to this day I suffer from chronic infections that are hard to shake off. For example I currently have a throat infection which has been ongoing for more than 6 weeks.

Section 7. Financial Assistance

55. I received the Skipton Stage 1 payment in 2004.

56. I received £23,500 which was authorised by the MacFarlane Trust when I was 18 years old. This was a result of the 1988 Litigation, for which I had to sign a waiver. I was told if I didn't sign the waiver then I wouldn't receive anything, and as I believed I only had 2 years to live I had no option than to accept. I had not even been told of my Hepatitis C infection at this point. I remember that the lawyer who advised me about the waiver wasn't even prepared to touch me because I had HIV.

57. After this I would occasionally receive things that I requested from the Trust. They provided me with an acoustic guitar, annual winter holiday grants, a specialist bed, moving grants and a contribution to specialist glasses. They would provide someone to help me fill in the forms for treatments and I generally found them quite useful. Initially I only received about £100 per month in financial support (this was at the beginning when the Trust first started) so I had to make regular applications for assistance. I remember my mother-in-law would have to bring us round food to help us get through the month.

58. I received a further top up payment of £20,000 from the MacFarlane Trust; however this was some way off what people with families received. After getting married I asked them if I was eligible to receive the extra that had previously been paid to married people, however they refused.

59. In the last 6-8 years the MacFarlane Trust has been much more difficult to work with. I have only really been able to get bed sheets from them and for anything significant, such as holidays, we are only offered a loan instead of a grant. I was given two £900 loans and then found out that the Trust had £2million in reserve.

60. I have only requested 2 things from EIBSS. Firstly a new mattress due to my terrible night sweats, and also some money for a holiday which was advised by a consultant as I needed more sun due to my bone density and increased allergies in the UK. Both requests were denied and I was told on the phone by EIBSS that they 'can't willy nilly give money to everybody'.

61. As of this year, under the current payments schemes I currently receive around £3,000 per month. This is therefore the first year I have been able to live comfortably and have any real disposable income.

Section 8. Other Issues

62. I believe it is extremely important that the Inquiry prioritises those who are in urgent need of care or housing, and look to implement immediate measures to support those people as they will not be able to wait until the Inquiry is over. In particular I believe that those infected should be passported through the benefits system. I also believe that there should be an exemption for bedroom tax.

63. When making decisions on the financial future of those infected and affected, it is vital that the monthly payment systems are continued and not replaced by lump sum compensation, as we need a secure future instead of a short term fix. I also think that lump sum payments should be made available.

64. I would like the Inquiry to look into what happened with the reserve money held by the MacFarlane Trust. It was set aside specifically for people with HIV

and those who were co-infected, and I want to ensure that the money continues to help those people.

65. I also think the Inquiry should look into what happened at Arkansas prison regarding infected blood, and the involvement of Bill Clinton.

Anonymity

66. I do not wish to be anonymous.

67. I do not wish to be called by the Inquiry to provide oral evidence.

Statement of Truth

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

Signed.. GRO-C ....

Dated........24/11/2018..........

MEDICAL SUMMARY
(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

15.12.1989 Letter from Ian Franklin (Consutlant Haematologist) QE Hospital, Birmingham. It has been brought to my attention through complaints by patients that confidential discussions have been carried on in the waiting room prior to the Thursday morning clinic. All of you will be aware that there are a number of patients with haemophilia who have been infected with the AIDS virus (HIV) prior to 1985 in the course of treatment with Factor VIII concentrate. The implications of this infection have been devastating both in terms of patients individual health and the potential for ostracism and discrimination at work and in society at large. Because of this we have advised all patients to maintain strict confidentiality of their own HIV status in order to protect themselves against ostracism and discrimination....It is inappropriate for the issue of HIV positivity to be discussed within the open forum of the clinic waiting room. This is likely to cause embarrassment to patients who may or may not be HIV antibody positive and those patients who are HIV negative may fear that people will assume that they are positive, and similarly individuals who are positive may fear that their confidentiality is being jeopardized. Please respect your own confidentiality and that of others.

04.06.1992 Letter from QE Hospital, Birmingham advising of the recommendations on choice of therapeutic material from the Regional Haemophilia Centre Directors Committee.

09.07.1992 Consent form for change to BPL8SM being purer Factor VIII concentrate.

17.07.1992 Letter from QE Hospital, Birmingham. He is HIV seropositive but he is asymptomatic and he has been counselled about safer sex and how he must make sure that any sexual partner is informed of his HIV seropositivity and counselled independently to document this before they embark on having a sexual relationship. There have been new directives recently on recommendations of treatment of severe haemophiliacs who are HIV seropositive from the Regional Haemophilia Centre Directors Committee. These recommendations are that HIV seropositive patients should be treated with purer Factor VIII products.....He has accepted that he wishes his treatment to be changed.

23.10.1992 Letter from QE Hospital, Birmingham. Refers to a diagnosis of previous non-A, non-B hepatitis. I reviewed this young 23 year old for the first time since 1998. He is asymptomatic from his HIV point of view....

26.05.1994 Clinic notes. Stephen is asking about Hepatitis C....Dr Wilde...discussed Hepatitis C – offered apt at liver clinic – wishes to attend.

29.07.1994 Hepatitis C Assessment Clinic. Dr Ahmed, Dr Wilde. Fully counselled re hepatitis C and offered a liver Bx – has decided to accept this.

01.08.1994 Letter from QE Hospital, Birmingham. Steve was seen in our Hepatitis C Assessment Clinic...He was fully counselled with regard to Hepatitis C infection and offered a liver biopsy to assess his suitability for Interferon therapy. He has decided to take up the offer of a biopsy and we will therefore admit him in due course for this.

2003 Mouth ulcers/tongue lesions.

12.05.2005 Letter from Birmingham Children's Hospital (incomplete).
HIV – as you are aware, testing for HIV was not available until 1985/6. A that time they were testing for antibody to HTL V3 (that is what HIV was then called). A blood sample from you on 12.09.1986 tested

"positive for antibody to HTL V3 by Elisa". This was reconfirmed on a sample dated 30.09.1986. Where we had stored samples on patients we also obtained back testing. The earliest positive for HTLV-III antibody that we had for you was 1983. You would therefore have been infected with HIV prior to 1983.

HCV – testing for HCV did not become available until the early 1990's and you transferred from the Birmingham Children's Hospital to the Queen Elizabeth Hospital (QEH) in 1988. Any information on HCV status would therefore be in your QEH notes.

Treatment received – I am enclosing copies of your summary treatment sheets. From 1981 you were treated with Armour Factorate (F'ate, FVIII, factor VIII are all used as shorthand)....

May/June 2006	CD4 169 (classed as AIDS)
2007	Nausea, candida.
01.12.2009	Safeguarding alert because of issues with neighbours.
04.08.2010	Letter from QE Hospital, Birmingham. He commenced HAART therapy in October 2006 when his CD4 count fell....I started him on Truvada one tablet a day and Efvirenz....His HIV has been excellently controlled on this therapy.....With regard to his Hepatitis C infection he has a chronic mild transaminitis and a fibroscan performed last March gave a score of 4.9 which is very reassuring. He has declined proceeding to Hepatitis C eradication therapy until the new protease inhibitor drugs become available.