Witness Name: AP Hearne
Statement No: WITN1281001
Exhibits: WITN1281002-8
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANDREW PAUL HEARNE

I, Andrew Paul Hearne, will say as follows:-

Section 1. Introduction

1. My name is Andrew Paul Hearne of GRO-C GRO-C. My date of birth is GRO-C 1960 and I am single. I have elderly parents and a sister who have all been negatively affected by my infections as a result of receiving contaminated blood products. I have been unemployed for nearly 30 years due to my ill health.

2. **This statement has been prepared without the benefit of access to my full medical records.**

Section 2. How Infected

3. I have severe Haemophilia A with a 0% clotting factor. **Exhibit WITN1281002** is an extract from the National Haemophilia Database dated 23rd May 2007 illustrating the blood products I received between 1969 and 2005.

4. Throughout my life, I attended the Haemophilia Centre at the Churchill Hospital, Oxford (the hospital) and my consultants were Dr Rizza and Dr Matthews.

5. Neither my parents nor I were ever given any advice about the risks of receiving blood products.

6. I was infected with HIV and Hepatitis C as a result of receiving contaminated blood products.

HIV

7. I visited the hospital regularly to pick up my treatment and I recall having vague conversations with my consultants who advised me that I had AIDS antibodies which meant that I would probably not contract AIDS. I am now aware that their knowledge regarding antibodies was extremely poor at that time.

8. Nevertheless, in or around 1985 and during a routine appointment, Dr Rizza or Dr Matthews told me I had, in fact, been infected with AIDS. I was not given sufficient information to allow me to understand or manage my infection of AIDS but I do believe that the consultants themselves were only just beginning to understand the same.

9. **Exhibit WITN1281003** is a letter from Dr Matthews to my GP confirming "*For your information your patient's test was AIDS antibody +".* Unfortunately the date of this document is "*as postmark*".

10. **Exhibit WITN1281004** is a letter from Dr Rizza to me confirming that I had already been told that I was HTLVIII antibody positive by 20th February 1986.

11. **Exhibit WITN1281005** is an extract from my medical records confirming that I was HTLVIII antibody negative on 5th February 1985. This contradicts with **Exhibit WITN1281002** which records that my first positive HIV (HTLVIII as it was known then) was 14th August 1984. I believe that the HTLVIII tests were

unreliable and that the medical professionals themselves were only just starting to understand HIV at this time.

12. Following my infection with HIV I recall that the medical professionals advised that I must continue to be treated with Factor VIII because my clotting factor was 0%; I therefore required the blood products to stay alive. I do, however, recall a discussion with the medical professionals at this time as to whether I could move onto heat treated blood products. However, I was told that this was not possible because children took priority in relation to heat treated blood products

13. In relation to advice on managing and understanding my infection, to include the risks of transmission, I recall that I would have had a few discussions with Dr Rizza or Dr Matthews and I believe they may have given me some information at that time. However, as previously stated their knowledge was only just starting to grow in relation to HIV. In addition to the support of my consultants, and because of the uncertainty and lack of knowledge, I regularly visited a library at the Terrence Higgins Trust, in London and I researched issues pertaining to HIV myself.

Hepatitis C

14. I recall that in the mid1960s when I was aged between 6 and 10, I became jaundiced whilst on the children's ward at the hospital. I believe that I was infected with Non-A non-B (NANB) Hepatitis as early as then. I recall the doctors telling me that I had had a reaction to the blood products, and the plasma products could give me jaundice, they didn't explain how this happened.

15. **Exhibit WITN1281006** is a letter from my medical records dated 12th April 1972 from "*Secretary*" to Dr Mitchell-Fox regarding me confirming "*This Centre (the hospital) is taking part in a survey arranged by the M.R.C Cryoprecipitate Working Party in order to discover whether transfusion jaundice occurs in patients suffering from haemophilia or Christmas disease who have been treated with blood, plasma or plasma concentrates. If*

jaundice has not occurred, please complete and return the form at the foot of this letter. If jaundice has occurred, we should be grateful if you would complete and return the attached Form 3 giving details of the illness".

16. In the early 1980s, Dr Rizza told me that I was infected with NANB Hepatitis.

17. In the mid 1980s, I attended a number of appointments with Dr Trowell who sat me down and told me that I should reduce my alcohol intake. She was quite strict with me and every time I saw her, it felt a bit like she was lecturing me. I recall her telling me that I would probably die from issues with my liver before the HIV would kill me. I didn't really believe her, and I think it was an effort to get me to cut down alcohol. I recall that my Liver Function Tests (LFTs) showed abnormalities in my liver in 1988.

18. Hepatitis was always known as NANB and suddenly a reference was made to Hepatitis C and it felt like it came out of nowhere. I am unsure as to when I was told that I had been infected with Hepatitis C.

19. I believe that the medical professionals probably gave me a little information to allow me to being to understand my infection of Hepatitis (NANB and C).

Section 3. Other Infections

20. **Exhibit WITN1281007** is a letter dated 22nd January 2001 from Dr Giangrande and Dr Keeling to me confirming that I had received some batches which were donated by a blood donor who had nvCJD. The letter continues "*It is regrettable that the Department of Health did not follow the unanimous advice of the UK Haemophilia Centre Directors' Organisation (UKHCDO) and adopt the use of recombinant factor VIII some years ago as this problem could have been avoided. It remains a matter of concern to us that recombinant factor VIII and IX are still denied to most patients with haemophilia in England, although these products are now available to all people with haemophilia in Wales, Scotland and Northern Ireland. We shall continue to lobby on your behalf to obtain these products for all our patients.*"

21. **Exhibit WITN1281008** is an extract from my medical records dated 24th September 2009 entitled "*Confidential Patient vCJD Exposure Assessment Form*" which confirms that I was put at risk of vCJD.

Section 4. Consent

22. I was probably tested for various viruses without my knowledge and therefore without my consent.

23. I was used for the purposes of research without my knowledge or consent and I refer to **Exhibit WITN1281006**.

24. It is in no way a criticism or me being vindictive but I believe that the early HIV tests were unreliable and only in their infancy and being continuously developed.

25. I recall that on a number of occasions I was told that my blood was being stored and used for various unknown purposes. I would like to think that any blood taken from me was used to improve these early HIV tests.

26. I recall that on a number of occasions when blood was taken from me I was asked if more blood could be taken for Dr X, Y or Z for the purposes of research.

Section 5. Impact

27. The mental effect of having been infected with HIV and Hepatitis C as a result of receiving contaminated blood products is that I find myself in an unbelievably sad life. I genuinely do not fit in anywhere.

28. HIV has had a catastrophic effect on my life. I have ended up on my own having endured almost 40 years of struggles with constant health problems. This has meant that I have been continuously depressed, unhappy and lonely throughout my life.

29. Most of my friends have had children, some, now have families of their own, meaning that my friends can enjoy the company of their grandchildren. I am happy for them but it is heart breaking that I do not have a family of my own due to my HIV and Hepatitis C infections. I'm aware that I am already in the position that when my health deteriorates, I have no one to help and look after me.

30. My childhood and teenage years were difficult and school was not enjoyable due to my Haemophilia related struggles. Just as I had begun to enjoy life at the age of 24, started to discover girls and get some ambition; I was hit by the disaster of HIV. Not content with just being handed the horrible news of having been infected, I had to endure the fact that HIV related stigma was rife. Therefore, I had to keep quiet about my infection whilst watching those horrific adverts of the dangers of HIV on the television. I had to endure laughter when people made sick jokes on the subject. My future and prospects were taken away from me. Although my life did not end; it certainly felt like it had.

31. Physically, I did not take any antiretroviral treatments until 1999. I remember trying to research all the new treatments and studies on these and noting that they were perhaps not the best type of drugs to be putting into your body. I refused all treatments, including Septrin, despite the medical professionals wanting me to start treatment. By this time my CD4 count was dangerously low so I had no choice in the matter but to commence antiretroviral treatment.

32. I suffered with quite a lot of skin problems including seborrheic dermatitis which I believe was a result of my infections and is a common complication of HIV. When I went out in the sun, I went bright red which meant that when I attended events; even more attention was drawn to me which was especially upsetting because I was already hiding the very existence of my infections from people.

33. This reddening eventually turned to rosacea. I had a badly spotty face for 20 years until approximately 2 or 3 years ago. Through my own research, I found a new drug, which I had to pay for myself, but seems to be working.

34. Throughout the 1980s and 1990s, I suffered with pain in my ankles. I had nights when I took 6 painkillers which only "*touched the edges*" of my pain. When I wanted to get up in the night to go to the bathroom, I had to use walking sticks. During the day, I walked with crutches. It was a massive effort and a lot to deal with on top of the infections themselves.

35. Due to Haemophilia, I was unable to participate in sports or many hobbies, therefore a lot of my social life was spent at the local pub. As a result of my infections I had to start to cut down my alcohol intake; it had to gradually reduce every year for about the last 20 years, when, after a diagnosis of severe cirrhosis, I had to completely stop about 5 years ago. This has had a significant impact on my social life.

36. In 2002, I underwent the Interferon and Ribavirin treatment in an attempt to clear the Hepatitis C. I felt terribly ill during this treatment. I suffered with exhaustion and depression and as a result I was prescribed antidepressants. However, I also suffered side effects as a result of the antidepressant medication. At 30 weeks into this treatment, the doctors told me that the Interferon treatment was not working and they took me off it.

37. I then commenced a further treatment in 2012 which comprised of Pegylated Interferon and Ribavirin. The second treatment was also awful; I suffered from extreme exhaustion and I recall parking my car at the hospital for an appointment, walking 100 yards, and then having to stop and sit down in the reception area to take a break. I was also offered antidepressants during this treatment but I refused this medication because I had suffered side effects from these tablets during the first Hepatitis C treatment. The doctors discontinued this treatment when they realised that it was not working.

38. Following the two failed attempts at clearing my Hepatitis C, I did try to stay positive and hope for the best and await new treatments. However, it was

only about 3 years ago, after clearing the Hepatitis C with, a newly invented drug, Harvoni, that I started to feel a bit better and made an effort to improve my general health. I had a course of treatment with Harvoni which began at the end of 2015 and finished in early 2016; the duration of the treatment was about 2 months. I did not suffer any serious adverse side effects from this treatment. I actually recall getting a buzz from the Harvoni treatment for the first week , then some nausea and headaches, but it was bearable.

39. After approximately 2 weeks of commencing the Harvoni treatment, I was told that I had successfully cleared the virus but I had to continue taking the treatment for the full duration. After I cleared the virus, I was so pleased that I had got rid of this awful disease. I remember feeling very positive and putting a long Facebook status up to reflect this fact, revealing my previously fairly secret fact that I had Hepatitis C.

40. I had been suffering with pains and discomfort for years in my liver but my doctor said that there were no pain receptors in the liver. However, these pains eased after the successful Harvoni treatment.

41. I regularly look on the Harvoni Facebook page and post updates and reply to people who are about to undergo the Harvoni treatment. I put people at ease because I am able to confirm that I personally did not suffer any negative side effects as a result of the treatment.

42. I did have to fight for around 18 months to get the Harvoni treatment; but I fought because I knew that my liver was very bad by this time due to the biopsy I had had which confirmed severe cirrhosis (see paragraph 43) and without it my prognosis was very poor. My liver consultant, Dr Collier, completely understood that I needed to get the treatment and assisted getting me to the top of the waiting list. Dr Collier wrote to the consultants at Reading Hospital to see if they could treat me as soon as possible. I met the consultants in Slough for a consultation following which I was started on the Harvoni treatment.

43. Approximately 5 years ago, and after suffering terrible pain, I underwent an operation to remove my gall bladder and prior to this surgery I had to prompt my doctors to conduct a liver biopsy at the same time. The doctors were reticent to conduct a biopsy for many years due to the risk of bleeding due to my Haemophilia. However, I was slightly worried because my previous biopsy undertaken in 2002 had showed mild fibrosis of the liver and in the years following this biopsy, my Liver Function Tests (LFT's) had been deteriorating. Following my request, my present Liver Consultant, Dr Collier, wrote to the surgeon who was due to remove my gall bladder to request a biopsy. This was then undertaken and the results of which confirmed that I had indeed developed severe cirrhosis of the liver. I think that I was both shocked and surprised that my liver had deteriorated so badly this quickly. Although I was drinking very little alcohol by this time, just a few shandies, I immediately knew I had to completely stop. This was another big blow to my quality and enjoyment of life.

44. I suffer with a lack of concentration and memory loss and my recall is not as good as it used to be. My vocabulary has also suffered in that I struggle to articulate myself.

45. Although my liver is still severely cirrhotic the results of my fibroscans have slightly improved, and at present is functioning quite well. I have done everything in my power to assist my general health and wellbeing. I have lost weight, cook healthily, abstain from alcohol and try to exercise regularly. This has had a beneficial effect on my health which has recently improved. I can now walk more easily, and I am going to the gym for some gentle exercise.

46. My ambition is to get myself back out there in the world. Recently my friends asked me to accompany them to Lille in France on the train and I actually thought about it before politely declining. I do believe that it is a part of my subconscious which prevents me from getting more involved, but it is all a sad result of my infections and a total lack of confidence. In terms of socialising, I am trying to get myself out there and have recently joined a local choir, but I am finding this very hard as I realise how different my life has been compared to a normal life.

47. Therefore, given the improvements in both my mental and physical health, it came as a massive shock when my doctor recently told me that my spleen was enlarged. This felt like a kick in the teeth and a huge step backwards in my mental wellbeing and I started again thinking that my life was a bit pointless. I have often thought that I would put "*That was a bloody waste of time*" on my gravestone. I am seriously considering not having a funeral, and just having a quiet private cremation. However, I am trying my best to stay positive whilst waiting for further tests and clarification from the doctors in relation to my enlarged spleen. It does feel like I have had the longest terminal illness possible, over 30 years and the fear doesn't go away.

48. In relation to confiding in people about my infections, I did tell a few close friends about my HIV in the mid1980s and they were accepting of me and my diagnosis. I now appear occasionally to be outliving some of my friends, which surprises everybody including me. The initial prognosis was that I would not be around for very long but I am still here today, although as I mentioned, it's like having an extraordinarily long terminal illness. I believe that, compared to others, I have suffered very few negative experiences involving stigma, although I have avoided telling most people, and haven't the confidence to be public with my infections.

49. Occasionally, with some, I have been more open about my diagnoses because I feel, to some extent, it explains why my life was and is, so different, and why I was never married, didn't work, didn't have children, had not been on holiday for over 15 years, and didn't have many hobbies or interests.

50. I did have a couple of relationships but these didn't work out and finished as a result of my infections. Following this, I met a few ladies from personal adverts which they had placed in an HIV magazine. I remember meeting a lady called "*Night*" from Nigeria who I believe had won Miss Nigeria in a beauty contest. She invited me to an event in an organisation for HIV positive women, in London, and afterwards some of us went on to a nightclub. Night was a wonderful and beautiful woman. However, the date did not materialise

into a relationship. A few years later, I found out that she had died. It was terribly sad; she was so vivacious and full of life.

51. I did not continue with dating as it became too difficult and complicated with my infections and I therefore gave up. I have therefore not got close to anyone for about 20- 25 years but I sometimes think that I should try again and look for a relationship but I am still very wary in this regard, and never quite get brave enough to attempt it.

52. In terms of employment, I used to work as a Manager at a Travel Agency. I remember having to tell my boss that I had been diagnosed with HIV. She was understanding and professional with the news and duly disclosed this fact to the Area Manager who was shocked but quite kind, and supporting to me. I had a successful career then; I was doing very well and had built my way up in the company and planned to continue this upward path. Our Travel Agency was the 3rd largest in the country and I believe that I played a big role in its success. I know I was being encouraged to further my career by top management, I recall going for an interview for a more senior national role, but due to my ill health, which was deteriorating I was not able to accept or carry out a more senior role. I really enjoyed my career and I think I would have had an even better one but following my diagnosis, and continuing poor health, I suffered a total lack of ambition and drive as negative thoughts of my infection and poor prognosis of my life expectancy took over.

53. My health plummeted and it was apparent that my infections were taking over in or around 1991 which was when Dr Trowell wrote to my employer to support my application for early retirement on the grounds of ill health. This was approved and I took early retirement at aged only 31.

54. My infections have had a terribly negative impact on my parents. They have not been able to see their son have a partner, get married or go on to have children. It has been devastating for them not to have grandchildren. In the choir and an art club my parents used to attend, they were never able to relate to other members and friends who had grandchildren and it was a sad and isolated position for my parents to find themselves in.

55. Although my parents were always there for me and I sometimes used to confide in them a little, but not in detail about my health, this does not happen anymore due to their age. Our roles have now reversed and I look after them more now than they look after me. I regularly visit their home, help with their shopping and cook Sunday dinners for them. If I did not have the responsibility to care for them, I would try and put myself out there to do more charity work. Occasionally, I mention my infections or the Inquiry to them and their reactions show that they have been angry for many years. Yet, over the years they have kept all of this below the surface. So much remains unsaid.

56. When I was younger, my parents used to regularly take me to the hospital and care for me as a result of my Haemophilia although I didn't involve them or anyone else in the treatment, problems, stigma, and mental distress of the HIV and Hep C. During this time I did not realise just how much it all affected them. My father was always quiet and seemed distant when I was younger and could not really handle conversations about my infections and always changed the subject and likewise cannot really handle any conversation about health, either his own or anyone else's, making wills or future care which is a conversation that I have had to have with him more recently.

57. I believe that both my parents were and still are devastated and angry about my infections and I believe that both of them have both bottled up their real feelings about my HIV for many years. They are two old and sad people who do not have a large social life, and do not have much enthusiasm for life in general, which is very much as a result of what has happened to me. My infections have had a massive knock on effect and I believe that maybe if they had grandchildren then life would have been very different for them. They have also had to witness the suffering which I have endured for nearly all of my life.

58. Now, they rarely ask me about how I feel, and in a way, I believe that it is best for them not to know the entire truth. Recently, my mother told me that she wished I had some company in my life and suggested that I get a puppy. She knows that I am very lonely. However, I am very anxious and concerned as to

what will happen if I do not outlive my parents because they do, and will need an increasing amount of help in the very near future.

59. Over the years, I have confided in my sister. She was deeply upset by my infections however, GRO-C as she has gone through a very difficult divorce. She has been unhappy and can therefore offer little or no support to either my parents or I. She also has no children which devastates my parents as much as my lack of children. She tells me that our parents tell her that they worry about me all the time which is upsetting.

60. I think that all of my friends realise that I have had a very sad and lonely life. They have seen for decades how difficult life has been for me. It is unwritten and unsaid but they definitely are very aware of this, but don't know how to help me.

61. It is ironic really that I have a nice little house with a lovely view overlooking a lake and a nice car; but nobody to share it with and nobody who can appreciate these things with me. I have the attributes of a lovely life, but not the important people to share it with such as a wife or children. I have thought this every day for several decades as I walk around my home in silence, trying to find a point to life.

62. Throughout my life, there have been many "*ifs and buts*" in relation to what may have happened had I not been infected with HIV and Hepatitis C. Despite how hard I try to be upbeat, not a day passes when I don't become riddled with sadness and loneliness, whether it is reading, watching Television or going out. Everything is a constant reminder of a life that did not happen.

Section 6. Treatment/Care/Support

63. Once or twice during my ankle operations I was placed in an isolated room at the hospital.

64. Medical professionals tend to be fully gloved when taking my blood.

65. I attend physiotherapy sessions and at one time my physiotherapist suggested that I could join a gym to assist with my mobility. I was advised that I could get a discounted price on gym membership if I had a referral from my GP. I therefore asked my GP, who I have known for 30 years for a referral. However, she wanted to disclose my HIV positive status to the gym. I was angry and disappointed, and explained she really didn't need to do this. There was absolutely no reason to do as she wanted and this situation made me lose all respect and confidence in her. She eventually, after consulting a colleague, realised she was wrong.

66. When I tried to change dentists due to being dissatisfied with my current dentist's services I found that it was a stressful process as I had to disclose my infections and had to deal with a lot of prejudice. Eventually I have had to go back to a dentist miles away, who deal with patients with difficult medical histories.

67. Approximately 12 years ago I was due to undergo a colonoscopy at Wexham Park Hospital. A consultant from the Oxford hospital (Churchill) telephoned the Wexham Hospital in Slough to discuss the procedure and advise that I was a risk of vCJD. I was ready for the procedure and already dressed in a gown but the procedure was cancelled and rescheduled as a result of this telephone call.

68. In approximately 1985, I used to speak with Mary Fletcher who was a very nice nurse and social worker at the hospital for around an hour once per month. I believe this was a form of counselling but I do not recall how long it lasted for. I remember that I could see her virtually whenever I wanted. I remember that the reasons she left her job was because it was too much for her to handle as so many haemophiliacs were passing away.

69. Apart from the meetings with Mary Fletcher, I have not been offered any other counselling or psychological support which is hard because I suffer with

regular depression and have done so throughout my life. I have had counselling through the GP over the past 10 years but I had to instigate it myself and received it approximately 4 times. However, it has only been of some benefit.

Section 7. Financial Assistance

70. I received an initial payment of £20,000 and then a further £25,000 from the 1991 litigation which effectively set up the Macfarlane Trust (MFT). However, I was forced to sign a waiver in this regard. I also received regular payments of approximately £100 or £200 per week. I do not have many criticisms in relation to the MFT and I found them helpful on the telephone.

71. Approximately 12 years ago, I received a grant from the MFT for my my French windows, roof and bathroom. I felt my application was handled in a supporting and quite efficient way. It was fairly straightforward.

72. However, I never liked having the requisite annual assessment of finances and income.

73. I received the Stage One payment of £20,000 and the Stage Two payment of £50,000 from the Skipton Fund.

74. I now receive support from the EIBSS which is approximately £36,000 per annum.

Section 8. Other Issues

75. I do not think there is one particular answer to this tragedy. We absolutely should not have been buying blood from American prisons; therefore, I believe that the Government and pharmaceutical companies should be more

to blame than the medical profession. I believe that the medical profession were in a difficult position and should not really be blamed for this tragedy.

Anonymity, disclosure and redaction

76. I do not want to be anonymous and I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.... GRO-C

Dated....16th April 2019........