Witness Name: Mr N Weller
Statement No: WITN1598001
Exhibits: WITN1598002-4
Dated: NOVEMBER 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NEIL WELLER

I, Neil Weller, will say as follows:-

Section 1. Introduction

1. My name is Neil Weller. My date of birth is GRO-C 1971 and I live at GRO-C GRO-C I am the younger of two brothers. I have three children, GRO-C aged 17 GRO-C aged 14 and GRO-C aged 8. I met Hayley, the mother to my three children, in 1996 and we married in 1999. The marriage broke down in 2013 and we recently divorced. I live alone albeit the children visit with me every other weekend and during school holidays. I work 4 days per week as a Finance Assistant in the Accounts Department at Jesus College, University of Oxford. I have been in this role since December 2017.

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.

Section 2. How Infected

Method of Infection

3. I have Haemophilia A, classed as severe, with Factor VIII levels of less than 1%. I was diagnosed with the condition on GRO-C 1972 when I was 11 months old. The genetic link is unknown as my parents are not haemophiliacs. I have recently tried to research a potential genetic link on my mother's side of the family but have drawn a blank.

4. I have always been under the care and supervision of the Oxford Haemophilia Centre from diagnosis. From the 3rd January 1979 I was able to eventually have my Factor VIII administered at the Princes Margaret Hospital, Swindon (GRO-C). The PMH was demolished in 2003 and the local hospital in Swindon is now known as the Great Western Hospital. From 1993 when I moved to GRO-C I was closely monitored at the Oxford Haemophilia Centre. I was under the care of Dr Henry Campbell Drysdale at PMH until he retired in the early 1990s. Meanwhile I was always under the care of Dr Charles Rizza (Oxford Centre Director). He retired in 1993 and he was replaced by Dr David Keeling. Dr James Matthews was also at the Oxford Haemophilia Centre (Assistant Haematologist) until 1991 until he was replaced by Dr Paul Giangrande who the was appointed Director upon the retirement of Dr Rizza.

5. I was given Factor VIII blood concentrate since my diagnosis in 1972. I had many years where I needed a significant amount of Factor VIII. I had many bleeds to suffer with. Ankles were my main target joint in my younger years, and knees were more problematic from around 1983. I also remember and it is documented that I also had bleeds in fingers, elbows shoulder, hips and abdomen too. I refer to Exhibit WITN1598002 being a copy of my hospital treatment record from 28.07.73 to 27.03.01 and Exhibit WITN1598003 being a copy of the UKHCDO patient annual treatment record from 1974 to 2018.

6. Around 1980 my mother, June, started to treat me at home. The blood product would be dispatched by Oxford to our local hospital, in GRO-C and

we would collect it and administer at home. At around aged 12 or 13 I began to treat myself.

7. Between 1986 and 1995 I was in and out of hospital all the time and also for very long durations. I was a teenager, turning man and wanted to live a normal life. I was always in trouble with the hospital because I was getting bleeds all the time. When we had bleeds back then we would be in hospital for 5-8 weeks at a time. I was often treated on the Girldlestone, Gibson and Nani wards at the Nuffield Orthopaedic Centre (NOC) as well as a couple of instances on the John Warin ward at the Churchill, where the HIV sufferers would also be treated (and quarantined in side rooms). I lost about 7 of my friends to HIV. I am not sure how many I lost to HCV, but I believe there were many.

8. On 7th November 1993 (aged 22), I was diagnosed with Hep C.

Advice Given regarding the Risk of Infected Blood Products

9. No advice was given to my parents at any time about the use of or risks associated with blood products. I was diagnosed with haemophilia at infancy because of recurrent bruising. Patients and their parents put their trust in the doctors and we were all lead to believe that they would give you factor which and would make you better and help our bleeds. My mother and I trusted the doctors and medical staff. As a mother, when you see your child in agony, you just want them treated and for them to be eventually free of pain. You did not question them, you had no reason to. No advice was given to me subsequently. I was never offered a choice of product or recall being aware that there was a choice for the patient. I recall an occasion upon which I was admitted overnight at the Royal Infirmary Edinburgh. It was New Year (2nd January 1998) I had an ankle bleed and it was so severe I had used all the factor I had taken with me to Scotland and was immediately hospitalised because it was agonisingly painful. I recall the female haematologist there, Dr Jenny Craig, remarking to me that she was going to give me "the good stuff"

and *not* the "Dirty stuff you get in the South". I was then released the next day as my ankle bleed had recovered.

Discovery of Infection

10. I was told by Dr Paul Giangrande on 7th November 1993 that I had tested positive for HCV, sat in a hospital room during a routine follow up. I was 22 years old and also on my own. Dr Giangrande said something along the lines "There has been something in your blood for a while. It was previously called non-A, non-B but has recently been classified as Hepatitis C". He then said "From what we know it will not affect you too much, but if it does we have got you under the radar. You can carry on living an active life. It shouldn't affect you in any way." The tenor of the conversation made me feel that it was just 'one of those things' and that that was pretty much all there was to say and that Dr Giangrande could neither tell me more or knew nothing more than that.

11. The diagnosis was like a bolt out of the blue. I felt vulnerable and alone and did not know what it meant in terms of treatment and life expectancy. At one time I recall that I asked and was told that there was no evidence of Hep C being passed to others through sexual activity. I was later told that I had become infected as a result of the Factor VIII products I have been receiving since 1972 and because of that, it could not be explained to me exactly when I had become infected.

12. The apparent normality of my conversation with Dr Giangrande was reinforced by the 'matter of fact' type of conversations I had with my fellow patients. For example, If you told someone you had "Hep B" or "Hep C" they would often respond with "Oh yes I've got that" or, or in some instances it would be "yes me too and I've got HIV as well".

13. Following my HCV diagnosis, I was placed under the care of a liver consultant at the Churchill Hospital, Dr Joan Trowell. No information, advice, reassurance or treatment was offered. I was told that I would be monitored,

for signs of jaundice for example and I would have regualer liver function tests. It was only when Dr Joan Trowell retired and Dr Jane Collier appointed in her place on 1st October 1998 that I was given any hope. She seemed more knowledgeable and consulted with her patients in relation to treatment options. Up until then and from 1993 onwards, I had no idea what would happen to me and/or how long my liver would hold up.

14. I recall making contact with 3 or 4 solicitors in 1994/95 to see if I had a case to sue. That option/door was shut on me because I could not pinpoint liability.

15. I believe to have been tested HIV, HCV and HBV without my or my parents knowledge and without consent. I have spoken to my mother, June, about this at length recently and we were certainly not given adequate or full information pertaining to the testing. When attending the six monthly follow up appointments numerous vials of blood would be taken, sometimes as many as 6 or 7. No explanation was ever given as to why the vials were needed unless I asked. I formed the impression it was just routine. I would on occasion ask, to make conversation, usually to be met with a cursory response. My question 'What we taking bloods for today?" would usually be answered "just levels", "Antibodies" or "liver function tests". There should have been far more transparency.

16. I was aware of the risk of HIV and AIDS because of the high profile nature of the disease at that time and the fear and stigma surrounding it. I recall an incident at school when I was 12 or 13. A boy at school (being aware of my haemophilia) shouted at me across the room and in front of my classmates "Oi Weller, have you got that gay disease?" Everyone laughed and I felt defenceless. I did not know whether to say yes or no. I didn't have the answers.

17. In 1983 my mother, June, told Dr Drysdale of her worries for me about AIDS and was also concerned about hepatitis as she had been told that there had been some cases reported. She was by then treating me in administering the Factor VIII product to me herself. It was despatched to the PMH by Oxford

where she would collect it. She felt largely isolated and unsupported. I believe I must have been tested for HBV some time in or around 1982 (without my knowledge) as I was subsequently vaccinated for Hep B on 13th November and 21st December 1982 and 21st June 1983. My medical notes reveal that by October 1985, just two years after my mother was assured by Dr Drysdale and subsequently Dr Matthews that my risk of contracting AIDs was minimal (due to my having received largely UK product), I had been tested as many as four times for HIV.

18. In 2010 I obtained an incomplete set of medical records from Swindon Health Authority. I recently tried to get hold of them again and they said that all records have been destroyed. In February 2018 (just after the Inquiry had been announced) I attended the Haemophilia Centre and viewed my records. I had just 30 minutes to read through with someone looking over my shoulder. I believe a lot of information within my records has been withheld from me as I had not previously been copied in or made aware of it.

19. By way of specific example, I now have copies of two letters addressed to my parents (marked 'date as postmark' but appear to be attributed to 1985 or 1986) stating that I have been tested negative for HIV (one letter says 4 times and the other says 5 times). I had not been given prior knowledge of these tests. My mother has no recollection of receiving the letters and was never told of the tests. In fact she had been told that UK blood does not carry any risk. I would also add that up until 1979 all letters from OHC had a date on them and I would query why that policy changed given that people do not habitually retain envelopes.

Section 3. Other Infections

CJD risk (see paragraph 20 below)

Section 4. Consent

I was tested without consent (see paragraph 15 above)

Section 5. Impact

Impact of the Infection

20. In 2002 under Dr Jane Collier, I underwent a liver biopsy to ascertain the HCV genotype and enable me to commence the Hep C clearing treatment I potentially may have needed. I was duly told my HCV maybe treatable with Interferon and Ribavirin and I had a 60% clear rate but also was a 40% chance of failure and if that were to be the case then I may be considered for a second round of treatment, albeit being for a longer duration. I delayed the treatment process for a couple of years to enable Hayley to conceive and subsequently give birth to our second child, GRO-C I was told under no circumstances to risk Hayley to conceive whilst under the treatment and had to wait for six months after. It has been unbelievably hard for us to make the sort of long term decisions and life commitments to include marriage and planning kids that non-affected people are easier able to make. I have experienced ongoing worry and anguish about what else I might be subjected to. Around the time that GRO-C was born, to add to my worries, I received notification that I had been exposed to the risk of CJD via Factor VIII blood products.

21. I eventually decided to undergo the clearing treatment, Interferon tablets and weekly Ribavirin injections for six months from 4th January to 30th June 2005. As a reaction to the Hep C treatment, the physical symptoms I experienced was that of severe stomach cramps, flu-like symptoms, fatigue, lack of concentration and feeling tired and washed out. My stomach pains resulted in me being admitted to hospital twice for a suspected appendicitis, the first time in June 2005 and then again in February 2017.

22. The clearing treatment was what I can only describe as hell. I suffered with anxiety and depression and experienced sudden and dramatic mood swings, irritability and anger outbursts. Hayley GRO-C had to keep the children away from me. As a result I spent most of my time in the caravan parked up to the side of our house. 21 weeks into the start of the

treatment Dr Collier had considered halting the treatment as I felt I could take no more and threatened to 'do myself in'. I had to persuade her that I would not do and for her to continue to the treatment.

23. Three months after the completion of the treatment I was told that the Hep C had cleared. However my symptoms have persisted including the fatigue, depression, irritability, anxiety and mood swings and constant flu like symptoms especially bad every morning. .

24. Up until my clearing treatment I had been mentally sharp and had a career in accountancy. In 2001/2002 (prior to the clearing treatment) I would travel abroad to France, Holland and Germany to undertake job assignments. After the treatment I struggled to get professional jobs and hold down the jobs I acquired because I was worn down and depressed and struggled with a lack of focus and concentration. Even to this day at Jesus College I can only deal with a basic accounts position. I had so much potential to achieve a fantastic career before HCV and it upsets me because I am struggling now at forty-seven when I could be in a much financially stronger position otherwise

25. I was compelled to pay higher insurance premiums for life, travel etc. as I was regarded as high risk by any insurer. I was unable to obtain mortgage protection cover for sickness as the cost was prohibitive. Being unable to continue to work as an Accountant, I acquired a news agency in 2007 and had 26 staff working for me. I worked long hours to ensure it was successful. My wife Hayley was not much involved in the business and stayed at home to care for the children.

26. I refer to Exhibit WITN1598004 being a letter from the Oxford Haemophilia Centre to my GP dated 19th April 2013. GRO-C GRO-C Hayley and I split up just three months later in July 2013. We had been married for 14 years and had had three children together. The business folded the following year. My marriage had failed, Tesco had bought and refurbishment the premises next door and I just couldn't cope anymore. There were no contingencies in place and I did not think it would all fall apart but it did. I lost what I believe to have been

approximately £70,000 goodwill overnight. Debts had built up and I was emotionally drained and also needed a fusion and reconstruction surgery to my right ankle. Within a very short space of time, my world had collapsed. I had lost my wife, my children no longer lived with me, my business and was about to lose my home too. GRO-C GRO-C the building society were looking at starting possession proceedings. My home (adapted to accommodate my disability) was on the market for sale and I had 10 or 11 viewings over an 18 month period. I tried for eighteen months to sell but could not secure a buyer as my house had been adapted and would only be habitable to someone with similar disabilities.

27. In total I had five procedures on my right ankle to make it able to weight bear and I could not work between September 2014 and July 2017. The arrears to my mortgage built and today they are just over £30,000. My knee currently needs a revision procedure and as I put this statement together I have in the past few days been to A & E where the pain is so bad. I have been signed off work and should not be working on health grounds however I have too as Universal credit can in no way cover my financial commitments. Working 4 days per week drains me but I have no alternative to do so to keep my home. I had no issues with depression, moods and sharpness before treatment. I used to have so much energy and was the life and soul of the party. I used to light up a room but now my mojo has gone and I feel I can easily empty one. I am disinterested and have no zest to do things anymore. That has an affect on the children because I cannot lead an active life. I just sit in my chair every evening as I have no energy or stamina to do anything else such as chores or hobbies. Most my friends in the village meet up around the local pub once a month, but these days due to my lack of zest I always put in my apologies.

28. In terms of stigma, even my classmates knew haemophiliacs had HIV before I knew whether I had it myself or not. For job applications I did not put haemophilia on there because I was scared of the stigma. When I was much younger before the HIV coverage I would tell people I had haemophilia but then from about 12 or 13 I would only say that I had a football injury or

fracture for example because of the stress and anxiety that people would assume I was infected if I told them I had haemophilia.

29. Because of the amount of time I had spent in hospital in my youth, I had formed a close friendship bond with my fellow haemophilia patients. Friends passed away. I saw my good friend Jonathan, in his last days. I was admitted to the John Warin Ward in 1992 after a car accident. I remember many of my friends in separate rooms because they had HIV. I remember with sadness starting a conversation with someone "Oh is that's xxxxx xxxx, I wonder where the other xxxx boys are?" "Oh they've gone" (3 brothers, 2 already died). It was such a sad and sombre atmosphere as I learned they were all dying around me. I remember the funerals I attended. It was like a community in the hospital and the staff (the sister & doctor on the ward) came to my 21st birthday party and my wedding. They were also losing patients/their family the same ones they had worked so hard to keep alive over decades and now gone within a year of being infected. I am profoundly affected by their loss and continue to be, survivors guilt just isn't a phrase so sound cool, it really gets inside your head and effect your emotions every single day. I have come to terms in that I never got HIV or not a more nasty thread of HCV however each day you beat yourself up and think "Why wasn't it me". I believe we were all placed at risk. I query whether some of us were 'cherry picked' for the good stuff whilst the others were given risky or substandard product, but at the end of day we all got infected one way or another. I have never said this but some days, especially the journey I have gone through over recent years I wish I had died, and I know that sounds horrific but sometimes this journey has been a living hell and I just wished sometimes I hadn't survived.

30. I was diagnosed as having Hepatitis C, and was told that I had cleared Hepatitis C in 2005/6 but still suffer with constant flu-like symptoms and fatigue. This has impacted upon every aspect of my life on an ongoing basis to include my ability to work (with which I struggle) and my home life (with my children) and my social life. I rarely go out socially.

Section 6. Treatment/Care/Support

Treatment resulting from the Infection

31. Following diagnosis, I was more or less left for a 5 year period of time (1993-1998) to get on with things, without offer of treatment and without anything evolving or development. There was no procedure on how to get on with it. As patients we all had to go away and live our own individual lives. There were no focus groups, counselling or hugs. My post treatment has been lonely and hard, trying to explain it to people is difficult and people cannot comprehend how awful and worthless you feel. My positivity has been taken from me for so long.

32. Whilst I have been cleared of the HCV I continue to suffer with the same symptoms I experienced during the treatment. I continue to suffer with stomach cramps most mornings and flu-like symptoms most days. I suffer with, irritability, anxiety, depression and brain fog. The last 5 years of my life have been complete hell since marriage broke down. My business failed and everything got to me. I was determined not to have a breakdown however. I dug my heels in and got through it. I have not been offered any counselling as I was told that I was not suicidal and should get on with life. I later (this year) underwent some counselling of my own volition and expense.

Section 7. Financial Assistance

33. I received the normal monthly payments of £202 per month then a top-up allowance of £250 (until March this year) under the Skipton Fund. I also applied 4 years ago under the Skipton for a grant for new flooring. I did not really want to do so as I have tried to be financially self reliant throughout my life and it felt like I was begging for money. The last five years have been particularly hard for me and I needed the help more than ever.

34. I applied for an ex-gratia payment when the payments moved to EIBSS. I found it very stressful and it created a lot of anxiety as I had to basically re-apply with the medical information and I was worried I might not get it anymore. My GP was unable to assist and I had to the Haemophilia Centre twice with what felt like a 'begging bowl' it was such a relief when I got it in the end. In March 2018, EIBSS contributions increased as I was accepted at a higher rate because of my HCV symptoms. In July 2018 my top-up payments were reviewed. It felt like I was having to plead my case again and justify why I should get it. The process is totally unnecessarily as they should be able to access the history of their own applicants.

35. Because I am much slower than I was previously and now have what I describe as 'brain-fog' the applications take much longer and one application took around 2 weeks. Normally I would assume it would have taken me a couple of days to fill out these forms, but because they're so detailed and what seems complexed it takes a lot longer It feels like you are being scrutinised and analysed to get extra payments you need just to get by. I now get £1500 per month as a regular payment. Top-up is £810 a month but GRO-C GRO-C I have to pay for Maintenance and an I have to keep to an agreement so I could keep the house GRO-C GRO-C

36. I believe EIBSS to be worse than Skipton in some ways. There own calculations were apparently wrong and they wrote asking me to return the overpayments. Moreover I do not understand the basis of their own calculation parameters resulting in a clear disparity between payment awards.

37. The additional grants are equally as difficult. I applied for a respite grant to take a long overdue holiday during the summer of 2018. It took two months to receive the grant that's specifically for this purpose. I applied in July and got the money in September (after school holidays). The process involved 7 or 8 emails and 4 phone calls and 2 additional trips to the hospital to get the wording right so it word by word fitted into the criteria and also clarify who is

MEDICAL SUMMARY

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

Treatment Record

Copy Treatment Record from OHC 28.7.73 to 27.3.01 attached.

Treatment Summary

Copy Patient Annual Treatment Record from UKHCDO 1974 to 2018 attached.

going, why the holiday is needed and correct details. In the end I had to borrow money from my parents and pay them back. When the money eventually arrived it was £100 short than when I originally applied. As time progressed the cost of the holiday increased between applying and eventually booking due to EIBSS being so particular and the net effect it cost a lot more money in which I had to subsidise.

Section 8. Other Issues

38. After watching Jason (Jonathan's son) on Panorama I have attended a few meetings in London and spoke to others with HCV with the same symptoms as me. I had originally put it down to getting old but now have a better understanding of the side-effects of the treatment. I feel betrayed by those I turned to for trust and need answers.

Anonymity, Disclosure and Redaction

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

Statement of Truth

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

Signed **GRO-C** ....

Dated 15th November 2018.