Witness Name: NEIL WELLER
Statement No: WITN1598005
Exhibits: WITN1598006-13
Dated: JANUARY 2019

INFECTED BLOOD INQUIRY

SECOND 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

2. This is my Second Statement. It should be read in conjunction with my First Statement given to the Inquiry (Witness Number WITN1598001) on 15th November 2018.

Section 2. How Infected

3. I was infected with the Hepatitis C Virus (HCV) as a result of receiving contaminated Factor VIII (FVIII) concentrate. I was informed that I had HCV on 7th November 1993 by Dr Paul Giangrande at a routine appointment at the Oxford Haemophilia Centre. My medical notes and records are incomplete but they nevertheless reveal that I was identified as having HCV at least 9 months before I was informed of it by Dr Giangrande. Referring to paragraph 10 of my First Statement, Dr Giangrande intimated that I had had HCV

(previously referred to as non-A non-B Hepatitis) 'for a while' although it could not be explained to me exactly when I had been infected.

Section 3. Other Infections

4. In or around 2004 I was also notified that I had been exposed to the risk of vCJD through FVIII concentrate.

Section 4. Consent

5. I was tested for HIV, HCV and HBV without my or my parents' knowledge and without consent.

6. I was treated for HCV with Interferon in 2002 without being given adequate and full information in relation to the long lasting side effects. I refer to **Exhibit WITN1598006** being the letter from the Oxford Haemophilia Centre to my GP dated 19th April 2013 (also exhibited to my First Statement). The effects of the Interferon treatment I was given to include depression, irritability, sudden and dramatic mood swings, anger outbursts, chronic fatigue and brain fog caused the breakdown of my marriage just three months after my wife Hayley and I had told Dr Giangrande we feared as much. When we saw Dr Giangrade I was basically sent away to a nothing can be done scenario. It was only with the opening of the Inquiry and hearing the similar experiences of others that I fully appreciated that *I* was not the cause of my marriage destruction. *Interferon* was the cause. We were a strong couple for 17 years. My wife knew that I had HCV before we married. The Newsagents business I owned and managed folded the following year (in 2014).

7. Up until having the Interferon treatment I had a successful/lucrative 13 year career in Accountancy. I had an annual salary of around £38,000 salary and a company car. I occasionally travelled abroad to undertake job assignments for the companies I worked for. I was extremely sharp. The Interferon treatment destroyed my focus and concentration to the extent that I lost the ability to be able to think clearly at all. The decision I later made to buy an

already struggling Newsagents had disastrous repercussions. I was not fit to make that sort of decision on behalf of my family. No one in their right mind would have touched that business with a barge pole as it was genuinely a 'going concern'. The 'old' me would never have done so. It wasn't rational. I was not a well man but didn't know it. I was vulnerable. I then let the debts mount up and they spiralled into huge debt resulting in me believing I had to take out the IVA I ended up with which still has a hold on me even today. If I had realised then how badly the Interferon had affected me, I would not have had it.

8. In short having HCV did not make me feel unwell per se. I would have never had the Interferon treatment had I been aware of the long lasting effects. I would have waited for a better treatment.

9. In terms of being used for the purposes of research, I refer once again to the final entries to my UKHCDO Patient annual treatment record at **Exhibit WITN1598007**. It would appear that I was part of Dr Craske's research work. I was not aware of this. I do not know who Dr Craske is.

Section 5. Impact

10. I refer to my First Statement but it does not even begin to describe the enormity of the impact upon me of being infected with HCV through FVIII concentrate. Moreover, I cannot stress the level of trust my mother and I had in those treating me at the Haemophilia Centre and the level of our involvement and friendship with the staff and fellow patients with whom I formed very close friendships.

11. The doctors were more than family to me and they were, to me, Godlike folk promising advances in treatment and care second to none. My mother and I were involved with fundraising for the Centre (and the Haemophilia Society) doing jumble sales and the like and my Uncle also left a legacy in his Will to the Centre (an unknown sum to us). We were never told what became of any of the money incidentally. It kicks sand in your face to hear the Centre may

have been in the pockets of the pharmaceutical companies and may not have actually needed the money.

12. When I was 20, I began a three year relationship with a nurse who was constantly caring for haemophilia patients at the Nuffield Orthopaedic Centre and that is how we met. My girlfriend was faced day in and day out with us haemophiliac patients and the turmoil we were in at that time. It was around that time that I met and struck up a very close friendship with Jonathan Evans, the late father of Tainted Blood Campaigner, Jason Evans. My girlfriend and I were invited to many functions which included invitations (like a Christmas Party at the Randolph in Oxford) being extended to my haematologists at the Centre (Dr James Matthews and Dr Rizza). It didn't stop there. James Matthews and Dr Henry Campbell Drysdale (my haematologist at Swindon) were always part of my life and we have remained friends since.

13. I refer to **Exhibit WITN1598008** being a photograph of me handing a cheque for £1,200 to James Matthews after a 50 hour snooker marathon fundraiser in 1989 and a photograph of Dr James Matthews with me at my 21st birthday.

14. I also refer to **Exhibit WITN1598009** being a photograph taken at my 21st birthday of my good friend Jonathan, his then wife and Jason Evans, aged around 3 or 4. I visited my very good friend, Jonathan regularly and in his last days and it was very hard for me to lose him and the friends I have lost since through contaminated blood. The last time I saw Jason (until he appeared on Panorama) was at Jonathan's funeral. Jonathan's death was the start of my feelings of survivor's guilt.

15. Putting patient confidentiality to one side, I was also at the brunt of my girlfriend's experiences as relayed to me each day/night. As a haemophiliac myself it was horrifying to hear. It was close to the end of our relationship that I found out that I was infected with HCV (in November 1993) and I have often wondered if this was the reason we separated.

16. When I married Hayley in 1999, Jonathan's parents (Jonathan had passed away by then) came to my Wedding and sat next to James Matthews. I have often reflected that if James Matthews had known about the toxicity of our treatment, it takes audacity to sit chatting to the parents of a dead son who had died from HIV/AIDS from treatment administered on his say so, and I find it hard even today to get my head around it.

17. I refer to **Exhibit WITN1598010** being a copy of an email I sent to Dr Drysdale on 1st February 2019 and a copy of his response sent on 2nd February 2019. I refer specifically to the second paragraph of Dr Drysdale's response wherein he appears to admit that he would have treated me with non-British FVIII concentrate if that was all that was available to him.

18. I refer to paragraphs 6 to 8 above in relation to the side effects associated with the HCV clearing treatment. It was far worse than having HCV in my experience. The clearing treatment has proven to have destroyed my life. HCV is the silent killer but I was in relatively good health up until I started the 26 week course of Interferon in 2006.

19. When my marriage then failed, I deeply felt the loss of having our children living separately to me. They too were deeply affected and had to learn to divide their time between two parents rather than having them under one roof; and all the miles we all spent travelling for that to happen. Despite everything I would continue to be a good father to my children and remain constantly as a part of their lives.

20. Since making my First Statement, I have had further health issues that I believe to be connected to HCV and/or the Interferon clearing treatment. These health issues on top of the side effects I have faced daily since my HCV clearing treatment in 2006 have overwhelmed me. Last year (2019) was yet another horrendous year.

21. In January I had to have knee revision surgery having struggled on a loose kneee for approximately two years. I then picked up a very serious infection

that threatened it's loss/removal. I refer to **Exhibit WITN1598011** being a photograph of my then infected knee.

22. In March I had further surgery by way of knee washout. This was followed by a six month programme of Rifadin and Ciprofloxacin antibiotics (once they had worked out what bug it was) which I endured side effects second only to the hell I underwent with Interferon. The mind fog, lack of energy and lethargy I have suffered since the Interferon intensified and the agonising stomach cramps I previously experienced on the Interferon reappeared. It was brutal.

23. In May whilst on holiday with my partner in Portugal the retina in my right eye became detached (by 70%). I had to have an immediate detached retina procedure upon my return to the UK. There is a well known and documented link between Interferon and Ribavirin treatment and serious retinal detachments. A very quick google search throws up countless research studies. I refer to **Exhibit WITN1598012** being a small selection of the many readily available.

24. At the end of October I then had cataract surgery which was a consequence of the detached retina. I had waited months for and without being able to see properly. I then needed to wait until then for glasses after the proceedure, so in total I was off for a five months.

25. These serious health issues came at a cost to me of five months salary albeit less £77.40 per week SSP (for three months on SSP, and two months without SSP as the twenty-six week period had expired in total for the whole year). I believe I am approximately £6,000 out of pocket. Moreover I had meetings with my Accountant at Jesus College (my employer) for discussions about my return to work and strategy going forward in terms of reasonable adjustments. I was at that time afraid I was going to lose the position I had tried so hard to obtain in 2017, and even at the time of making this Statement my mental health is also compromised as I feel I am constantly letting my employer down due to ill health through no fault of my own.

26. In all three surgeries from March to October last year, I was placed at the end of the day on the theatre schedule. Even with the coercion from my haemophilia nurses in March to be brought forward in line with my factor cover this was denied. In October the Registrar going through the operation check-list told me I would again be at the end of the list. To this I remarked "Nothing to do with me being a risk and then the theatre having to be scrubbed afterwards then?". He admitted there was reference in my notes about the vCJD contamination risk. The anaesthetist also got a tongue lashing but failed to contest in any form of dialogue with me.

27. Finally just before moving house in December, I went down with a high temperature and came out in a rash. I could barely assist my partner with the move and ended up registering with and seeing a new GP (without any of my medical history) on the same day being 23rd December. It turned out to be a severe case of vasculitis, a condition known to be caused by HCV.

28. My health issues persist with another recent hospital admission in January this year. I refer to **Exhibit WITN1598013** being a notice placed outside my side room warning everyone passing by that I am isolated as a health risk. When I was sent down for x-rays (three in total) the staff donned rubber gloves and wiped down the metal film cartridge between each exposure, something I have never seen in all my years and found it OTT. I wonder how long I have to exist free of symptoms of vCJD before I am no longer deemed a risk, another 20 years?

Section 6. Treatment/Care/Support

29. I have not been offered any counselling and have only had some counselling very recently of my volition and at my own expense.

Section 7. Financial Assistance

30. I refer to my First Statement outlining the difficulties I have encountered in dealing with the Skipton Fund and EIBSS. I also experience the lack of assistance due to mortgage arrears because I was unable to obtain Mortgage Protection Cover. As yet my solicitors, the Hep C Trust and the Infection Inquiry team are at a loss in how I can keep my mortgage lender off my back and harassing me every month when I am going to pay off my arrears. Just standing still financially is incredibly difficult and again giving me more unnecessary stress and pressure that could have so easily been prevented if I hadn't been infected with HCV. On its own trying to hold down a job with haemophilia alone is a hard task within itself without this added pressure added up top.

Section 8. Other Issues

31. There are no other issues.

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 ....15/1/2020...