Witness Name: Nathan Arthur Ian Reid
Statement No: WITN1486001
Exhibits: WITN1486002
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NATHAN ARTHUR IAN REID

I, Nathan Arthur Ian Reid, will say as follows:-

Section 1. Introduction

1. I am Nathan Arthur Ian Reid of GRO-C, Cornwall GRO-C. I was born on GRO-C 1976. I had an older brother, who died from AIDS related Pneumonia in 1986. I had another brother who passed away from a brain haemorrhage, aged 7, before I was born. My father has died but my mother is still alive. I am married, with two daughters, Hannah and GRO-C, who are twenty and seventeen.

2. I was infected with Hepatitis C as a result of contaminated blood products.

3. 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

4. I suffer from Severe Haemophilia A and I was treated with Factor VIII at the City Hospital, Truro (now closed). I have obtained records from the UKHCDO which states that I received Kryobulin between the years 1977 and 1998, Factor VIII (BPL) from 1977 to 1993 and two treatments of Oxford Factor VIII in the years 1981 and 1991. There is now shown to me marked WITN1486002 a copy of the UKHCDO records.

5. Up to the age of twelve, I was treated at the City Hospital in Truro. From 1986 onwards I have been treated at RCH Treliske Hospital in Truro ("Treliske"). Up to the age of eight, I went to hospital for treatment if I had a bleed. From the ages of eight to twelve, my mother treated me at home. From twelve onwards, I treated myself. I believe the infected blood was given to me the first time I was treated with Factor VIII when I was less than one year old. My brother and I were both haemophiliacs and we always had the same batches of Factor VIII not necessarily at the same time. There was only ever one different batch of treatment that he had, which I did not, and I believe that batch must have been infected with HIV.

6. My mother has told me that she was not advised about any risks associated with Factor VIII treatment.

7. After my brother passed away from AIDS in 1986, I was tested three times for HIV. The first two came back as inconclusive and the third one was negative. I believe I should have been tested for Hepatitis C when they were testing me for HIV. In fact the results of the HIV tests ought to have picked something up.

8. I do not know when I was tested for Hepatitis C, but I found out about the infection in 1991, when I went to the Haemophilia Centre at Treliske Hospital for

a nine month routine appointment. My mother had accompanied me to the hospital. On finding out, I was only fifteen and Dr Daly provided me with information that the virus was infectious and told me it was passed by blood or sexual intercourse. Since I had started a relationship with my current wife, and we had been together for over a year, I would have liked to have received more information although in the company of my mother, I couldn't say much. I remember it being a five minute discussion. I believe the information about the infection should have been given to me much earlier.

9. The information about Hepatitis C was communicated to me in a very clinical way, with no emotional support. I was told to come back and see them if I had any problems.

10. The only information I was given about the risk of others being affected was the advice Dr Daly gave me about having protected sex.

Section 3. Other Infections

11. I believe that I have been exposed to nvCJD because I was given a batch of blood from someone who died from nvCJD on GRO-C 2004. The blood product was Replenate. It was given to me in March 1997 and April 1997.

Section 4. Consent

12. When I was a child, my mother knew that I was treated with Factor VIII, because that was the treatment for Haemophilia A. She would have given consent for my treatment.

13. I do not believe that my mother was given adequate or full information about the product. She was not told about the risk that I could be exposed to infection from

blood products and she was not therefore able to provide informed consent on my behalf.

14. My mother consented to the HIV tests, but she did not consent to the Hepatitis C test and we were not aware I had been tested until I received my diagnosis.

15. I am not sure whether I was treated or tested for the purposes of research. I remember that some samples of tissue were taken from me.

Section 5. Impact of the Infection

16. The mental effects of being infected with Hepatitis C have included mood swings, memory loss and brain fog. It causes difficulty in communicating, thought forming and making decisions. Anxiety and stress seem to exaggerate the symptoms. The more you try to convey what you are trying to say, the more stressed and anxious you become. It's a vicious circle. Since clearing the infection it still remains an issue, but it has improved slightly.

17. As far as physical effects are concerned, the infection has made me very tired and I was not a normal teenager. I had no energy or stamina.

18. In about 2004, I was diagnosed with liver cirrhosis. Up until then, I had been under the care of one consultant haematologist. My care was then split between that haematologist for my haemophilia, and a hepatologist for my liver. over the next few years I was diagnosed with an enlarged spleen, varices of the oesophagus, gall stones and oedema of the legs. I was also diagnosed with compensated cirrhosis, which means that my liver is heavily scarred and will only perform the basic liver functions. I was given medication for the oedema, to reduce the swelling, and medication for high blood pressure to treat the varices of the oesophagus. I still take this medication.

19. In 2012, I entered discussions about treatment for the Hepatitis C. I had avoided any treatment up to this point due to the knowledge of the terrible side effects and the likelihood that it would probably fail. It was around this time that the new combinations were being trialled. A place became available on one of the more promising combinations under the care of Professor Cramp. The trial had to be halted for me, as after a few weeks I was getting sunburnt through UVB protected glass and showing symptoms of severe anaemia. It was at this point I was told that my liver was now decompensated and that I would be put onto the liver transplant list. At that point, they decided that it would be a good idea to put me through all of the pre-op tests to avoid any delays when the transplant became available. After a short break I was offered a trial of another experimental drug combination (Daclatasvir and Sofosbuvir) whilst I was waiting to climb the list, which I agreed to. After 12 weeks of treatment, during which there were very little side effects, this was successful. I cleared the Hepatitis C in 2014. Although I believe that I am still on the waiting list, my liver function has improved enough to carry on without the transplant for the time being. My local Hepatologist arranges for six monthly liver scans and blood tests to ensure that this stays the case for as long as possible. All of my Hepatitis C treatment took place at the Derriford Hospital in Plymouth.

20. Prior to the start of the initial trial it was picked up in a blood test that I had Diabetes. It was later diagnosed that I was Type 1 and am now on lifelong insulin treatment.

21. The Hepatitis C had an impact on my general medical care. I had dental care at the hospital. For a while, they would not give me routine check-up appointments and was told to only come in for required treatment. I then developed toothache, and they put me back on the list for 6 month check ups. I also have to have endoscopies for the varices and there is specific equipment that is only used for patients with specific infections.

22. The loss of my brother from AIDS and my own infection played a big part in the way I behaved towards friends. I used to be so frightened of friends or family finding out about the infection. I pushed people away, because it was easier to do this than to explain that I had Hepatitis C. I would even avoid telling new acquaintances about suffering from Haemophilia for fear that they would make an incorrect connection between that and the viruses. From previous experiences the stigma was enough for people to avoid you or talk behind your back. To avoid those situations I would lie to get out of awkward conversations or take a different route to avoid bumping into people. To anyone looking in I would probably be described as ignorant, untrustworthy or not a person that you would want to get to know. Another reason for distancing myself from people, especially those that were close to me, was that I didn't want them to have to suffer if anything bad happened. It sounds ridiculous looking back at it now, but it's how I felt most of the time until I was in my mid 20's. As a result of this I now only have a couple of close friends.

23. The infection has had a substantial effect on my marriage because we have had so many arguments about unnecessary things. Minor issues become major. Luckily my wife has been my rock and is very understanding. We have been together since we were fourteen and she has gone through everything with me. If it wasn't for her, I wouldn't like to think what would have happened.

24. I have missed out on family life. If I am having a bad day due to my energy levels, mood swings or just not feeling up to socialising, my wife would take the children out whilst I stay at home. Over the years, they have missed out on me being around and we have all missed out on memories that should involve us all. We did not tell my children about my infection until they were around 15. They knew that they should not share toothbrushes or towels. If I cut myself shaving, the towel went straight into the wash.

25. I believe there is a stigma attached to having Hepatitis C and it has strongly influenced my behaviour, as I have described above.

26. I found out about the Hepatitis C around the time that I was doing GCSEs. I left school when I was 15 and went to Cornwall College. I qualified in panel beating and spraying cars.

27. After leaving college, I set up my own business in making signs. I had a friend who worked for a newspaper, and he asked if I would like some work to earn extra money. I started in the post room for a few hours a week and worked my way up to a full time IT technician. Over the following twelve years I worked my way up to being one of three Regional Lead IT Technicians for Cornwall, Devon and Somerset. This came with a good salary for Cornwall (£26,000 + company car). I had also been offered a position at the Daily Mail Headquarters in London with a large salary increase, but due to my medical situation I decided not to take on the roll. Towards the end of my employment I began to find that I was falling asleep at work and did not feel that I could continue. Looking back this was due to the Hepatitis combined with the Diabetes. At that time, my employers were making staff redundancies, so I decided to volunteer for redundancy. My manager wanted me to stay but I felt it was time to go, I wasn't performing to the levels that I knew I could in the past. I went back to my sign writing business as it's what I knew and that I could get by on it. Although it is still running, I wouldn't say that it was thriving due to the amount of effort I can afford it. I work on my own from home and my wife works as a nursery teacher.

28. We do not have enough money and we survive solely on my wife's income, Family Tax credits and payments I receive because of my infection which I go on to describe in Section 7. We have two daughters to care for and they are both financially dependant on us.

29. My mother has been very affected by my situation, in particular, because of the tragedy of my brother's death, which she never got over. He was 19 when he died. My mother feels guilty about the situation and blames herself. She has a defective chromosome, which is why my brothers and I had haemophilia. I did not have much of a relationship with my father. My mother dealt with us. He only became involved if we needed a lift or something practical. He died 18 months ago. My mother lives in GRO-C and still talks about my brother.

Section 6. Treatment/care/support

30. No counselling or psychological support has ever been made available to me in consequence of being infected, and due the expense of such sessions, I never pursued it myself.

Section 7. Financial Assistance

31. I discovered the Skipton Fund through the Tainted Blood Facebook group. Following this, I applied for assistance and acquired the Stage 1 lump sum of between £20,000 and £25,000. When the Skipton fund announced they would be offering an additional payment for Stage 2, I had already qualified as I had cirrhosis of the liver. Stage 1 and Stage 2 came to a total of £50,000. In addition to this, at the time I acquired the Stage 2 payment, I received monthly payments of £2,095 which includes the discretionary payments.

I recall that the application proceed was very demanding and they wanted to know many details that to me did not seem relevant. I did feel as though they were actively trying to avoid paying out to people if they did not fit very strict criteria. The Skipton fund required my biopsy results to prove that I had cirrhosis. Luckily this had already been done, but to put a haemophilic through this is highly dangerous. A questionnaire was also sent to me which I needed my doctor to complete.

Section 8. Other Issues

32. Having an infection like Hepatitis C goes far beyond the infection and its side effects. It dominates every waking moment of your life. Every little strange feeling, twinge or pain leads you to think that it might lead to something more sinister. Stressing that everyone you meet may find out that you have the infection and the stigma that it would lead to. Then there's the constant lethargy of just existing. Everything is an effort! Obsessing when you cut yourself or have a nosebleed, that you have cleaned every little speck of toxic spillage up as you don't want anyone to have to go through this. Then multiply all of the issues with the added impact of suffering from Haemophilia itself – aching joints on top of already battered, bruised and arthritic joints.

33. You would think that when you have cleared an infection, as I have, that you would be free to live your life without worry. You're not. Yes, the symptoms improve slightly over time and you no longer have to worry about passing the infection onto anyone else. It's easier to tell people your story, albeit only to a slightly wider circle, but you still have death and his scythe hanging over your head in the form of either liver failure or liver cancer, both of which are highly likely and will shorten your life considerably.

34. The schemes (such as Skipton and EIBSS) that have been put into place to make payments to the infected need to be looked at as they are not fit for purpose. For a group of people that have already experienced enough stress and anxiety in their lifetimes it is disgusting that they have to go cap-in-hand and basically beg for money to live on. We as a group have lost our ability to work and mostly not through choice. Why should we be belittled into having to fill out form to replace incomes lost? Why should I be expected to live on less than half of the income per annum that I was earning in 2012? I know that it is not the inquiry's intention to look at compensation (not that they are that), but something

needs to be done to replace what should have and would have been ours had we been able to continue with a normal life.

35. I'm 43 years old now, I've missed out on so much of a normal life and it is all, in my opinion, down to one reason. The people in charge at the time either wanted or needed to save money and they put that over the safety of patients.

36. Some also wanted to use us as lab rats, to see what the effects of the different viruses would do. I believe that I was a PUP (Previously Untreated Patient). It may or may not be written in my medical notes, but I, like others of my age, were used in this way. Perhaps this was to inform decisions at a later date when it became an issue to the general population. Whatever the reason someone needs to be held to account for the pain and aguish that the have caused and they need to understand what they have done.

Anonymity

37. I do not want to be anonymous and I do not want to give oral evidence at the Public Inquiry.

Statement of Truth

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

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

NATHAN ARTHUR IAN REID

Dated 4th April 2019