Witness Name: Joseph David Monaghan
Statement No.: WITN4183001
Exhibits: WITN4183002
Dated: 12th August 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOSEPH DAVID MONAGHAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23rd April 2020.

I, Joseph David Monaghan, will say as follows: -

Section 1. Introduction

1. My name is Joseph David Monaghan. My date of birth is the GRO-C 1983 and my address is known to the Inquiry. I intend to speak about my experience of becoming infected with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

2. I do not wish to be anonymous for this statement.

Section 2. How Infected

3. I have haemophilia A, which is mild and I receive Factor VIII to treat my haemophilia. I don't often require treatment for my haemophilia, I typically

receive treatment once every few years, usually in response to trauma. I was diagnosed with haemophilia fairly soon after my birth.

4. I contracted hepatitis C after receiving Factor VIII to treat my haemophilia sometime between the age of eleven and eighteen months old. I cannot say which of these treatments caused my infection but I contracted hepatitis C as result of receiving Factor VIII during that period. I received these treatments at the Glasgow Royal Infirmary. I would not be able to say what doctor was in charge of my care at that time.

5. Neither of my parents were given any information about the potential risk of infection posed from receiving Factor VIII beforehand.

6. I was diagnosed with hepatitis C when I was eleven years old in 1994, I cannot remember the exact date. I had been receiving treatment in Yorkhill Hospital, Glasgow in response to trauma in my knee. During that treatment, my parents and I were told by Dr GRO-D that I had hepatitis C and that I had contracted the infection around ten years ago. I was not tested for the infection that day, they already knew about the infection and my positive result was waiting for me. We were under the presumption that they had known for a very long time. At that time, Interferon treatment was available for hepatitis C and they were ready to begin treating me with it that same day. They already had my first dose ready to go after I had been informed about my infection.

7. As far as I can remember, at my appointment they told me that the infection was nothing to worry about. I was only eleven years old at the time so when they told me it wasn't that serious, I believed them. I remember they made an effort to ensure my parents didn't believe it was anything serious either. That was all we were told really, they then began talking about how the Interferon injections would work and discussing the treatment with us. At that point we had no idea that other haemophiliacs were dying of these infections, we were not told anything about that.

8. We received virtually no information at all on the day of my diagnosis, it was not adequate for us to understand the infection at all.

9. I feel I absolutely should have been informed about my infection sooner than I was. They told me that I had the infection for ten years on the day of my diagnosis, I feel disgusted that information was withheld from my parents and I. It felt like haemophiliacs were being used as guinea pigs, it was like the information was deliberately withheld in their own self-interest.

10. The way I was told about my infection was absolutely horrible. It was ridiculous that something as serious as hepatitis C could be sprung on me like that.

11. We were given some information about cross infection at my diagnosis but we were told that was another thing not to worry about. We were told that cross infection could only come from blood to blood contact and because I was eleven, that wouldn't be an issue.

Section 3. Other Infections

12. I have not contracted any other infections other than hepatitis C.

Section 4. Consent

13. I believe I was tested without my consent as a child whilst receiving treatment for my haemophilia. I would constantly be tested for things and not be told what the tests were for. They knew what they were looking for but did not inform me any stage.

14. I believe I was tested without my consent. They knew about the progression of the virus in my body long before they told my parents or myself about the situation. The only way that would be possible is if they had been testing me for it without my consent.

15. I think I was treated and tested for the purposes of research. I think that was the purpose of the entire situation, I think they wanted to give us contaminated blood products so they could better understand this new virus in a test population.

16. I think one of the most damning pieces of evidence I have is a letter that was sent from A.F. Pettigrew at Yorkhill Hospital to a Mr Christie of the Armour Pharmaceutical Company on the 15th March 1984. I exhibit this letter as **WITN4183002**.This letter details a trial they were trying to put me on as a, "suitable untreated haemophiliac". The letter then goes to say that if any "suitable candidates do appear unexpectedly, we will be able to enter them on the trial without delay". This letter shows that even as a one year old baby, I was potentially going to be part of a trial that my parents were never made aware of.

17.

Section 5. Impact

18. It's only in recent years that the permanent long-term mental effects of hepatitis C have been discovered. Depression, anxiety, higher blood pressure levels that cause inflammation in the brain to name a few. Being someone that had carried the virus for over thirty years, information like that is very distressing. The stress of these symptoms developing in myself has been impossible to ignore.

19. Just knowing what the NHS did and how they treated me and people like me, has affected my mental health for years. I suffer from depression and I think I have been on pretty much every anti-depression medication there is. Even with medication, it still affects my life.

20. It is hard to tell how the infection has impacted me physically. It's not always as simple as feeling pain in my liver, which does sometimes happen. All I can say it that it has impacted my health for decades.

21. As a result of my infection, I was close to F3 level fibrosis of my liver around ten or fifteen years ago. I almost reached the point of liver cirrhosis before I began the treatment that cleared my infection five years ago.

22. My first treatment was a course of Interferon injections I received through Yorkhill Hospital under the care of Dr GRO-D on the day of diagnosis in 1994. The treatment was meant to be a six month course but ended up being eighteen months. We were told that the treatment would only be six months but when it had not cleared the virus at the six month mark, they said they wanted to see if it would work better if I received it for longer. At the end of the eighteen months, I was tested and shown to have cleared the virus. However, during a confirmatory test six to twelve months later it was discovered that the virus had returned. Interferon was the only treatment available at the time so there wasn't anything else for them to give me. All we were told at the time was that Interferon does not work for everyone.

23. I received my second treatment around five years ago and this treatment was successful. I cannot remember the name of this treatment. I do remember that this treatment was one of the first rounds of oral medication for the treatment of hepatitis C. It involved taking around twelve pills a day, six in the morning and six in the evening, for around twelve weeks. I was tested at the end of the twelve weeks and I was shown to have cleared the virus. I still get tested every year to assess whether the infection remains cleared but that treatment seems to be working for the time being. I received this treatment through a Gastrointestinal Specialist I found here in Illinois.

24. As I understand it, the reason for the gap between my first treatment and my second was that there was nothing shown to be successful that was available in that time. As far as I am aware, it is only in the last few years that these successful oral treatments have become available.

25. I did not face any difficulties in accessing either of my treatments. I am lucky enough to receive medical insurance through my work that allowed me to receive my successful treatment. I think the cost was somewhere in the region

of $50,000 to $60,000 without it. My insurance was pretty good so I think I only had to pay around $100 for my treatment in the end.

26. As an eleven year old child, the mental effect of going though Interferon treatment was very difficult. At that time I think I was still a little too young to fully understand the gravity of situation. It was a long time ago but I know that I was very unhappy during that time.

27. Physically, I still have nerve damage around my thighs because that was only place I could inject the Interferon without being feeling extreme pain. The treatment really took a toll on me, it felt like having the worst flu of my life for a year and half.

28. With my second treatment, I don't really recall any adverse mental or physical symptoms from the medication.

29. I don't recall my infection ever affecting my treatment for anything else.

30. Now, I am engaged to my new partner and we hope to be married next year. Having to tell someone you love about an infection like hepatitis C is extremely difficult. Having to do it twice is even harder. It is a very long story to have to explain and having to break down the potential complications was pretty scary. I suppose that was the effect the infection had on my family life, it was basically a precursor, to me having one.

31. My infection had a big impact on my parents. At first they weren't told a lot about the virus so they weren't that concerned but when more and more information started coming out about hepatitis C, they were scared to death. It was already hard for them to see me grow up with haemophilia but when the infection came around, it just made it a lot worse for them. They were disgusted when they found out I had been infected by the treatment that was meant to help me, it was a hard pill for them to swallow.

32. It's hard to say whether my family or I have been impacted by the stigma associated with hepatitis C. Nothing malicious has ever been said directly to

me that I can remember. But you never know what someone might think or say about you, when you're not there though.

33. I am not sure whether my infection had any impact on my education when I was a boy. I have ADD but I do not know whether I have that as a direct result of the infection or whether that developed on its own, but that would affect my ability to concentrate in school.

34. I remember having to take a few days of school at the start of my Interferon treatment due to the side effects but I wasn't off for very long.

35. My infection has not impacted my professional life.

Section 6. Treatment, Care and Support

36. I have not faced any difficulties in accessing treatment, care or support as a result of my infection.

37. I have never been offered counselling or psychological support as a result of my infection. I have pursued counselling myself and have been going to therapy for a few years now.

Section 7. Financial Assistance

38. I received £20,000 from the Skipton Fund sometime in the either 2004 or 2005, I cannot remember the exact date. I found out about the Skipton Fund after my aunt had seen something on the news about the fund and passed on the information to my Dad. I cannot remember exactly when this was but it was around a year or two after the Skipton Fund was set up. To apply to the fund, I contacted Yorkhill and got all my medical records. I then found some old medical transcripts in my records that showed I had been treated with Factor VIII products as early as 1984. I then sent those transcripts in along with the written application I had requested from the fund and my application was approved pretty much immediately. I did not face any difficulties in applying to

the fund, everyone I dealt with was very nice and it felt like they were there to help.

39. I received an additional £30,000 from SIBSS around three or four years ago. I also receive a monthly payment of £1,500 from SIBSS and those payments began around a year and half ago. I found SIBSS through my own research online. I was always looking online for any developing news or information about the infected blood scandal and came across SIBSS around six months to a year after they took over from the Skipton Fund. I then reached out to them and they sent me out an application form. I think I also received a letter about the fund at my parents' address as this was the address I had used for my application to the Skipton Fund. The application was pretty straightforward, it wasn't something that required anything from my doctor. I think most of my information had been carried over from the Skipton Fund. I was a little surprised about the self-assessment approach to the application for the monthly payment. It felt a little odd that it was left to our own opinions about ourselves but I found that refreshing, giving us that control. I did not face any difficulties applying to SIBSS either, they were very helpful and were able to answer any question I had.

40. I think the funds are a good thing but what they offer falls far short of what I feel people like myself deserve. As far as I know, across the other countries that have dealt with similar infected blood and blood products scandals, Australia, Canada and Ireland for example, the average rate of compensation is around $1,100,000 to $1,400,000 per person. I don't know if those people just received infected blood accidentally but I feel that the NHS actually sought out haemophiliacs like myself to conduct their own research into hepatitis C. I won't be happy until our compensation reaches the average compensation those in other countries have received. The haemophiliacs that were in infected in the UK in the 1980s were used as guinea pigs by the NHS and I don't even know if there would be a sum that could compensate that.

Section 8. Other Issues

41. I have no other matters to raise with the Inquiry, for this statement.

Statement of Truth

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

Signed GRO-C (Aug 27, 2020 11:30 CDT)

Dated Aug 27, 2020