

Witness Name: Angela Agusta

Statement No.: WITN3533001

Exhibits: WITN3533002-004

Dated: 24/9/2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF ANGELA AGUSTA

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 July 2019.

I, Angela Agusta, will say as follows: -

#### Section 1. Introduction

1. My name is Angela Agusta. My date of birth is [GRO-C] 1961 and my address is known to the Inquiry. I have previously worked as a [GRO-C] [GRO-C] but am currently unemployed. I am at present a carer for my partner, who I have been with for eleven years.
2. I intend to speak about my infection with the Hepatitis C Virus ("HCV"), which I contracted as a result of being given an infected blood transfusion.
3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment I received and the impact the virus has had on my life.

4. I would like the Inquiry to know that I intend to make a claim against Cork Hospital in the Republic of Ireland and that my intention is to see Malcolmson Law in Dublin to seek legal advice. However, as my infection was discovered in the United Kingdom and my treatment is taking place here, I would like to submit a statement to the inquiry so they are made aware of my circumstances. I am happy for the inquiry team to assist me with this statement.
5. There was a look-back exercise in Ireland to find people who were potentially infected during the period of infected blood use. However, they were unable to find me as I had been moving around.
6. I can confirm that I have had explained to me the use of my statement form. I am happy to sign a consent form on the basis that it will be submitted when my statement is signed.

## **Section 2. How Infected**

7. I believe that I was infected with HCV on 15 September 1984, at St. Finbarr's Hospital, Cork, following a haemorrhage that required a blood transfusion while giving birth to my third son. As far as I am aware, this is the only blood transfusion I have had. I did not find out I was infected with HCV for thirty-five years.
8. I recall that, whilst I was in the hospital giving birth, I started to feel faint and noticed that I was bleeding. I shouted for help and called for a nurse to attend to me. I was standing in the middle of a bloodbath and was terrified that I was going to die. I was taken to theatre and when I woke up I was told I had a haemorrhage. I believe that I must have had at least two units of blood. I am not certain of this, but I may have also had a Dilation and Curettage operation ("D&C").

9. I was not made aware of any risks associated with my blood transfusion. However, as it was a life or death situation for me, the decision was taken out of my hands.

Diagnosis with HCV

10. In 2015, I was diagnosed with Polymorphic Light Eruption, which meant that I was allergic to the sun, [WITN3533002]. I had a twenty-year history of recurrent photosensitivity. The effects involve rashes all over my body, which can appear immediately after as little as fifteen to twenty minutes of sun exposure.
11. After having many tests done by my General Practitioner, I was referred in February of this year to Dr Vernikos at St. Helens and Knowsley Hospital. He informed me of a new treatment available for my skin condition, as I was still having particularly bad flare-ups. The medicine I was to be placed on was called Methotrexate. In order to take this medication, I had to have blood tests and chest x-rays.
12. I received a phone call in March 2019 and was told that Dr Vernikos wanted me to have another set of blood tests. I went to my local hospital and picked up my form from the desk. Whilst I was waiting for my number to be called I glanced at my blood form. It was hard to make out the writing but I believe it said, 'tested positive for HCV and PCR' and something about genotypes. I was suddenly gripped by panic, as the form at the time looked to me as though it said HIV and not HCV. All sorts of things raced through my mind.
13. When I went in to receive my blood tests, I said to the nurse: '*this isn't for HIV is it?*' She said no but did not say anything else. No explanation of what the test was for. I did not want to push the issue so I did not ask any further questions. However, I couldn't shake the feeling of fear that I felt.

14. When I left my appointment, I informed my partner of what had just happened. She reassured me that it was probably routine checks before I was due to start on my new medication for my skin condition. I felt very upset and had a terrible feeling of dread after what I had seen on the form but I tried to carry on as normal for the sake of my family.
15. On 19 March 2019, I received a letter from Dr Vernikos [WITN3533003]. This letter stated that after testing some antibodies, there was a detection of HCV and that my liver function tests were slightly deranged.
16. I was devastated and in total shock when I received this letter despite my previous worry. My heart sank, I was numb and I felt sick. I was completely blown away. They could have at least brought me to the hospital and told me. I remember thinking that this was not a very nice way to find out. My current partner was also devastated by the news after thinking it was just routine.
17. I was not told that my blood tests in March included being tested for HCV; I thought they were part of a routine check for my medication associated with my Polymorphic Light Eruption.
18. On 5 March 2019, I had a US abdomen test, [WITN3533004]. The doctors informed me that there was a shadow on my liver. This was before my diagnosis with HCV, so they must have had some suspicion that I may have been carrying the virus. The results showed that I definitely had slight scarring and fibroids. Hopefully the treatment I am currently undertaking will help with this.

Treatment Given for HCV + Information Received

19. I was not contacted or given any information until 26 April 2019, when I was called to see the specialist nurse at St. Helens and Knowsley Hospital; I remember her name was [GRO-D]. She asked me if I knew why I

had been called into the hospital and I responded by saying: '*Have I got Hepatitis C?*' She then confirmed that was the diagnosis.

20. I recall that she told me that there were treatments available but that they were very expensive and my case would be put forward to get this approved by the NHS. She informed me that once I cleared the virus I would be feeling a lot better, that I would feel less foggy and confused. She did also inform me of the Inquiry and gave me a card for a liver helpline. [GRO-D] did not give me any precautionary measures to take or details on how to manage the infection; I only learnt this information through my own research.
21. I did ask [GRO-D] if I could have infected my kids throughout the years and she said no. I remember it was just left at that and she carried on telling me about the medication. She said that I would be put forward and that I would be seen very soon. I started my treatment around mid-June of this year.
22. After doing a bit of research, I contacted the Hepatitis C Trust as I was worried about my infection and wanted to obtain more information. I remember speaking to someone called Samantha and she informed me that [GRO-D] should not have said what she said about my infection, in relation to the possibility of infecting my children.
23. I am currently on a sixteen-week course of Elbasvir/Grazoprevir, which I take in the form of one tablet a day, and Ribavirin, which I take three times a day, again in tablet form. The effects of this medication will be discussed further under Section 5. Impact.
24. I have had blood tests conducted to see if the virus is still detectable and at present I am clear of the virus albeit I have still two weeks of medication to continue with as of the 17<sup>th</sup> of September.

### Thoughts On Process

25. I do feel as though I should have been given information in relation to my infection earlier. I believe that I should have been told when asked to go for a second set of blood tests, that there was a chance I was infected with HCV. Instead I was left in the dark and nervous, wondering what was going on.
26. I do not know why it took so long for my diagnosis with HCV to surface. In the late nineties/early two thousand's, I had an operation on both my legs at Peasley Cross Hospital and I wonder why it was not picked up then. I have had a lot of blood tests done over the years and often complained to my doctors of exhaustion and fatigue but my infection with HCV was never picked up.
27. I have not told six out of my seven children that I have been diagnosed with HCV. I have not told my ex-husband about my infection. I plan to tell them when I visit them in August in Ireland. I have told my daughter and she was fine with the information I gave her.

### Section 3. Other Infections

28. I do not believe that I have contracted any other infections as a result of being given an infected transfusion. However, I do believe that I have suffered in many other ways. As previously mentioned I suffer with Polymorphic Light Eruption, which I believe may be connected to my infection with HCV. This, along with the various ways that I have suffered throughout my life, will be explored in Section 5. Impact of this statement.

#### **Section 4. Consent**

29. I have been asked if I believe that I have ever been treated or tested without my knowledge or consent and the answer is no, I have always consented to my treatments.
30. As stated in Section 1. How infected, I was not told that my blood tests in March were being tested for HCV; this was done without my knowledge. I was told I needed to go for blood tests, which I consented to, but I was not told what this was for. I just assumed it was for my skin condition.
31. I do recall that I was in hospital for several days after my haemorrhage and was taken to theatre. I remember being asked if I would mind the student doctors having a look at me; I must have consented and said yes. I was then taken to another part of the hospital to what looked like a classroom to be looked at. I was put before the student doctors but I cannot remember what for or why. I found the experience and the fact they were discussing me very weird.

#### **Section 5. Impact**

32. The mental and physical effects that I have experienced as a result of being infected with HCV without knowing for decades have had a huge bearing on my life. This is especially true, as I for many years did not know what was wrong with me.
33. I noticed throughout the previous years that I had chronic fatigue and did not feel just right. However, I couldn't put my finger on it and did not think much of it at the time, although I did tell my doctors how I felt on occasions, but to no avail. Nothing was picked up despite the numerous blood tests that I underwent over the years and I find that both strange and very frustrating – could I possibly have been treated earlier?

34. In the nineties, I went to A&E because I had a strange feeling in my head. After having several tests, the doctors told me that I was ok and I just moved on with life.
35. I remember that, even after having tests, I knew something was wrong with me. People would tell me something and I would forget it straight away; it was like my brain was foggy. I could not repeat things straight after people had said them because I would simply forget. I often lost my train of thought during conversation. Once, I told my General Practitioner about my symptoms and he said there was something not right with me, I had no energy and felt down. He said that it was most unlike me and conducted more tests but couldn't find anything wrong. When I think back, I felt as though I was having some kind of psychiatric disorder.
36. Other physical symptoms I have had to deal with are constant joint problems. My wrists and ankles. In particular, I have had bad problems with my knee for which I have to take medication, including steroids. I have lost nearly two stones in weight and endure bowel movement problems. I also suffer constant chills and sweats. These can appear at any time.
37. I have also suffered with Rheumatoid arthritis since 2015 and Meniere's disease. My blood pressure has also increased so I am on a lot of medication to control these conditions. I do wonder if these diseases are also linked to being infected with HCV.
38. As far back as 1987, I have suffered from skin rashes all over my body. Over the years my skin condition became more severe and in 2015 I was referred to the Salford Royal Hospital for photo-patch testing. I was diagnosed with Polymorphic Light Eruption, [WITNW3533002]. I cannot say for sure but I do strongly suspect this condition is linked to my HCV. It will certainly be interesting to find out if there is any connection. It seems strange how I developed skin problems three years after my transfusion, when I did not experience these problems in the years before.



39. Other symptoms I have experienced include an interrupted sleep pattern. I have difficulty sleeping even when exhausted. Memory lapses as mentioned; I remember a time in 1990, when I went to town with my son. When I arrived home, I realised that I had forgotten him at the supermarket and I had to go back and get him. I did not know what to think at the time because I had been to the doctors and they had not diagnosed me with any conditions.
40. Now that I have been diagnosed with HCV it makes sense why I was experiencing all of these symptoms. I believe that at the root of all my problems is my infection with HCV.
41. I have been struggling a lot with my medication for HCV and have been experiencing various side effects as a result of my current treatment. It has been quite a traumatic time for me. I have been crying a lot and struggling with the situation I find myself in. I have not been my normal self. My personality is changing and people in my house have said that I am a nightmare to live with. I have become aggressive, even though I am normally a quiet person. I feel as though sometimes I am losing my mind, so I get frustrated and smash things up. I have no energy and my body is in constant pain, which makes me feel angry, sad and I also feel dirty but I am unsure of why.
42. On 17 June 2019, I had an appointment with one of my GPs, Dr Crompton. I told her about my treatment for HCV and the pain it was causing me and my difficulties with sleeping. She prescribed me some Zomorph Capsules, which is a type of morphine; she also put me on Zopiclone, which is a form of sleeping tablets to help me sleep at night.
43. I had also asked Dr Crompton if the results from my liver test had come back; she informed me that my liver was fine. However, when I went to St. Hellier Hospital to collect my medication I was told that my liver was showing slight scarring and that there were fibroids appearing!

44. In July I returned to my surgery as I felt I had a problem with my blood pressure. This time I saw Dr Booth. My pressure was high and he altered my medication. I asked the doctor if I could receive more painkillers and he told me no, that morphine cannot be prescribed if you have liver problems. I explained to him that Dr Crompton had prescribed the morphine earlier but he still refused. I am annoyed at this as I feel as though I have been passed from doctor to doctor with no thought about my feelings or communication. None of them seem really interested in my condition and I feel are often just going through the motions.
45. In relation to stigma, not enough people know about my infection as it is quite recent and I prefer to keep it that way. I have been pretty much confined indoors since I started treatment. I have not wanted to tell people in the town I live in as anybody with HCV would be labelled as junkies, drug users and prostitutes.
46. I do however go out to my daughter in laws to see my grandchildren. I am normally a very hands-on grandmother but now my infection with HCV has made me feel and act strangely around them. I do not want to touch them or kiss them in case I pass this nasty disease onto them. Sometimes, I just feel like not being here anymore or running away from it all. My head is just a complete mess trying to deal with all the fallout.
47. I have notified my dentist of my infection and the dental surgery has been fine with my diagnosis with HCV, they have treated me when I have needed dental treatment.
48. When I told the specialist nurse about these effects and the way I felt, she reassured me and explained that the medication can often make people feel like this. She also informed me we could lower the dosage but that if I hang on I would feel much better in the end.

49. As mentioned, I am pretty much housebound at the moment because of the treatment I am receiving. It has affected my social life and going out. I have also been stopped from going abroad.
50. My infection with HCV has also had a great impact on my working life. I used to work as a forklift driver in 2004 but had to leave my position due to fatigue and memory loss. I do believe that I may have been able to progress further in that career which I really enjoyed. However, my fatigue affected me so badly as a safety issue that I was forced to give up work after a couple of years. Still, back then I did not know what was wrong with me or why I was so tired at work, it made me extremely emotional. I attempted to find out what was wrong via my doctors but nothing was forthcoming. I would have worked on but my career was cut short. I may have been promoted so I do believe that the fact that I had to leave employment so early in life has also had a negative financial effect on my life.

#### **Section 6. Treatment/Care/Support**

51. I do not believe that I have faced difficulties or been denied access in obtaining treatment in relation to my infection with HCV. I know that I was relatively quick in accessing treatment compared to other parts of the United Kingdom.
52. I can confirm that I have not at any stage been offered psychological support to help manage my infection with HCV and the results of the consequential treatment.
53. During my interview with the Inquiry, I have been informed about access to the support mechanism that the British Red Cross provide.

### **Section 7. Financial Assistance**

54. As previously mentioned in Section 1. Introduction, I am seeking to make a claim against Cork hospital in the Republic of Ireland. I have an appointment with Malcolmson Law in Dublin, to receive advice and pursue any financial assistance that I am entitled to.
55. I have not contacted anyone yet in the United Kingdom to see if I am entitled to any financial assistance here.

### **Section 8. Other Issues**

56. I would like the Inquiry to know that I have not been happy with the way in which my General Practitioners, especially at Dr Husain and Partners, have dealt with things over the years. I was ignored when I needed help. I brought my symptoms to their attention on many occasions and I feel I was let down. Even now that they are aware of my infection with HCV no one has thought to ask how I am. I just feel like another number to them. I saw Dr Booth at the surgery and asked him about my infection with HCV and he told me that it has nothing to do with them and that it is to do with the hospital. I felt like they were not interested.

### **Statement of Truth**

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

Signed GRO-C

Dated 24/9/2019