GM.

Witness Name: George Manson
Statement No.: WITN042701
Exhibits: **WITN042702 - WITN042705**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GEORGE MANSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 September 2019.

I, George Manson, will say as follows: -

Section 1. Introduction

1. My name is George Manson. My date of birth is GRO-C 1966 and my address is known to the Inquiry. I am currently working for a supermarket and am trained as a Chef and Restaurant Manager, having worked in the food industry for many years. I currently live with my wife, Neli, and our twin babies.

2. I intend to speak about my life after contracting Hepatitis C ("HCV") from a blood transfusion. In particular, the nature of my illness, how the illness has affected me, the treatment I have received and the impact it has had and continues to have.

3. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement. The Inquiry team has explained anonymity and I do not require any information to be kept private.

4. My wife, Neli, was present at my interview with the Inquiry team.

Section 2. How Infected

5. While my mother was pregnant with me she suffered from German measles, and due to this and other complications I was born with one valve in my heart that never fully developed. In June 1974, when I was seven years old, I was the first male, and only the second person in the UK, to have an aortic coarctation operation. This operation took place at the Royal Hospital for Sick Children in Edinburgh. This was a major life saving operation, whereby my chest was fully opened up and two of my ribs broken in order for the doctors to access the heart valve. I was then required to stay in the hospital and convalescent hospital for about six weeks after the operation.

6. Following the operation I recall waking up in hospital with multiple tubes attached to me. I remember my mum was so shocked to see me lying in hospital in the state I was in; she even fainted at the sight of all of the tubes attached to me. I remember my Mum mentioning the blood transfusions I had received after my operation. Although Mum mentioned that I had received blood transfusions, she said there was never any conversation about consent, and as far as we were concerned it was an operation and that was that. We were happy that I was having the operation in order to save my life. I was only a young child at the time, but I understand from my Mum that she was never informed, or aware at the time that there was any risk that I may have received infected blood as part of the operation.

7. I was required to return to the Royal Hospital for Sick Children every couple of months. Subsequently, I attended hospital once a year, for a check-up on my heart. These check-ups would include the taking and testing of my blood.

8. GRO-C

GRO-C

GRO-C. We didn't hear anything further from the NHS, and were never contacted with the results of our blood tests.

9. Later in 2014 my wife and I attended an appointment GRO-C Dr Tong at a private hospital, Spire Shawfair Park Hospital ("Spire Shawfair") in Edinburgh. GRO-C GRO-C A few days after the initial blood tests at Spire Shawfair I received a call from Dr Tong who said that we were required to come into the hospital for a meeting as there was something he wanted to discuss.

10. My wife and I arrived at Spire Shawfair to be told that my blood tests had come back positive for HCV, and that the reason they asked us to come in was because they did not want to tell me this diagnosis over the phone.

11. Dr Tong initially asked me if I knew whether I had HCV, to which I answered 'no'. Dr Tong then asked me a series of questions regarding how I could have come to be infected with HCV. He asked me whether I had ever injected drugs, did I have any tattoos, piercings, or whether I'd had any blood transfusions or operations abroad. As I have never taken drugs and have no tattoos, I explained that I had only ever had one operation for my heart in 1974. Dr Tong then said that based on my answers to his questions, the blood transfusion was the likely source of HCV.

12. When my wife and I were told of my HCV diagnosis, initially neither of us knew what this meant, or really knew what HCV was to be honest. We both thought that HCV was similar to Hepatitis A and Hepatitis B and that it would not have a great impact on our lives. I asked Dr Tong if there was a vaccine available, to which he answered 'no'.. Despite Dr Tong's response, my wife and I still held out hope that a new drug or treatment would be developed soon. GRO-C

GRO-C

13. Following this appointment I was initially confused, and then became really angry. Following my operation in 1974 I had been back to hospital at least once every year for follow up appointments and blood tests. I can't understand how it was never discovered that I have HCV earlier, or even alerted that contracting HCV could have been a possibility. I also don't understand why I was never provided with my test results from when I'd had blood tests done GRO-C GRO-C at Ninewells.

Section 3. Other Infections

14. I have not contracted any other infections, besides HCV, from having a blood transfusion. GRO-C I have been tested for other infections such as HIV and the tests have all come back negative. My wife has also been tested and her results are negative.

Section 4. Consent

15. As I was a young child at the time, I did not consent to receiving the blood transfusion in 1974, and, to my knowledge neither did my mother on my behalf. I understand that the operation I underwent in 1974 was to save my life, and that a blood transfusion was administered as a necessary part of this surgery. I know my mother would not have consented to me receiving blood if she had been aware of the risks.

Section 5. Impact

Treatment and physical impact

16. After being referred by Dr Tong back to my GP, I was then seen by a Gastroenterologist at the Victoria Hospital in Kirkcaldy, Fife. The Gastroenterologist told me that Interferon and Ribavirin would be the most effective treatment for me. I was given a leaflet regarding the medication and a prescription for the Ribavirin tablets and sent on my way. There was no discussion about side effects of the treatment. Additionally, there was no mention of the effect that such medication may have on my heart. Obviously, the doctors were aware of my heart operation but it was never mentioned that the treatment could affect the rhythm of my heart.

17. I received my first injection of Interferon in January 2014. I attended hospital for my first courses, so I could be shown how it was done. I recall the injection felt like a bee sting, but about ten times worse. It left me bruised, and to be honest, a right mess. During the first few days of combination treatment with Interferon and Ribavirin I had awful cramps throughout my body. I have always been relatively fit and healthy but I was vomiting and had diarrhoea along with being freezing and shaking non-stop. I also experienced a spongy feeling in my hands, like carpal tunnel. I also felt depressed during this time. Whilst having this treatment I kept a diary where I recorded how I felt and effects that the treatment had on my body. Copies of diary entries from 13 January 2014 to 20 January 2014 are attached as **Exhibit WITN042702.**

18. Ten days later I attended hospital for my second Interferon injection, however, I was shaking so badly, struggling to breathe and the doctors were concerned about the effects the Interferon might be having on my heart so I was admitted to the Accident and Emergency department.

19. That day I suffered from a heart attack and was then transferred to the Cardiology ward where I stayed for around nine days.. The cardiologist then stopped my course of Interferon and Ribavirin treatment straight away. I was advised that the HCV treatment would have to be stopped for a year in order to protect my heart. I was told that I could be given no treatment whatsoever for HCV so that my heart could heal.

20. A few months after my first heart attack I suffered from another micro-heart attack. One of the valves which goes to the lungs burst which resulted in blood spilling from my mouth. I tried to keep it a secret from my wife but after three days she found out and said that if I didn't go to the GP straight away she would inform them herself. Following this I then saw my GP and was told that this could have been very dangerous. The doctors were left to argue over which should be treated first, my heart or HCV.

21. In October or November 2014 I was told that there was a new treatment available for HCV, Daclatasvir and Sofosbuvir. I was informed that I could start on this treatment right away and see how I got on. The doctors said that it was a relatively new drug

but that they were about 99% sure that it would work. Due to the newness of the drug and uncertainty of how I would react to it, I do recall feeling like a guinea pig at the time.

22. I had to take one of each tablet a day for ten weeks (in addition to the four or so tablets that I would take for my heart). A week or so after I took the first Daclatasvir and Sofosbuvir tablet I was feeling much better already. I had no side effects from taking it, which was completely different from the first round of treatment on Interferon and Ribavirin.

23. I finished treatment for HCV in early 2015. The day after I completed my course of treatment, I was admitted to Glasgow Royal Infirmary for an operation on my heart. I was sent to Clydebank for this operation, as it was where the specialists were based.

24. The treatment for HCV was successful and am now clear the virus (PCR negative). Now when I receive letters from the hospital in respect of HCV they usually just say, 'No further complications', and that's that.

25. Following the ten weeks of treatment I went back to the Victoria Hospital every month so my blood levels could be checked, I now attend hospital every six months for blood level tests, and once every year for an ultrasound and full blood checks.

26. My liver now has secondary cirrhosis and scar tissue damage. It frustrates me that for so long medical professionals should have known that my liver was being damaged but this was never followed up with further blood tests or correspondence to alert me that this may be a possibility, instead I heard nothing.

Mental

27. During the short period I was taking Interferon and Ribavirin, in addition to the terrible physical effects, I experienced depression. At the time I kept a diary where I would note down how I was feeling. I have kept a copy of this diary.

Employment

28. I used to be a chef and restaurant manager and would work extremely long days; sometimes 60 or 70 hours per week. Although I did feel exhausted at times with some pain throughout my body, I dismissed these symptoms as I thought feeling tired was just a part of what I did,. I just accepted that this was a general tiredness, and to be honest I am not the type of person who would just go to the doctor for this type of thing, so I never thought anything more of it.

Stigma

29. Being in the restaurant industry I always worked weekends. This didn't allow much to get distracted or to worry about any stigma.

30. I told some close relatives about having HCV. However, there are a lot of people I haven't told about my HCV diagnosis, even close family members and friends. I'm not actually sure why it is that I didn't discuss this with them, it may be that they wouldn't believe me.

31. After I found out that I had HCV then every time I accidentally cut myself I would put gloves on to make sure that there was no risk of contamination. I would always be conscious of sharing bottles of drink at work, and in social settings, where beforehand this is not something that I would have worried about.

Family Life

32. **GRO-C**

33. **GRO-C** **GRO-C** This made me feel like I was a leper who couldn't be touched.

34. Once I was declared PCR negative in 2015, GRO-C

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35. GRO-C

GRO-C our twins were born last year.

36. We have been told by the Gastroenterologist that our children are too young to be tested for HCV, but we were also told that there could be about a one in ten chance that our babies could have been born with HCV.

37. My wife has been a constant support throughout this process. When I had to be hospitalised in 2016 for my heart surgery, I was only supposed to be in the hospital for ten days, which turned into five weeks because of complications. As a result of this hospitalisation I was off work for about three and a half months in total. This meant that in order to be able to pay the mortgage and bills my wife had to start a second job, and was working both full time and part time jobs and taking overtime shifts for both.

38. Life could have been completely different over these past five years if I hadn't faced these struggles, and hadn't been fighting with the NHS for support. My wife and I eventually decided to try and stop talking about these things at home because we just wanted to try and move on. My wife and I together are there for each other and are able to face any issues that we have head on; together we are strong enough.

Section 6. Treatment/Care/Support

39. I cannot understand why I was still being treated with Interferon and Ribavirin considering my condition and despite the known negative side effects. I understand this treatment was stopped in other countries, including America, long before the UK stopped.

40. I received my course of Daclatasvir and Sofosbuvir treatment under the NHS, but many of the doctors and nurses at the time would comment on the cost of the drug, saying words to the effect of "did you know it's costing the NHS £120,000". I feel as though they were trying to make me feel bad or guilty about the cost of the treatment. Obviously, if it had been my fault that I had HCV I would probably feel bad for accepting the treatment, however when it was entirely not my fault that I was now living with HCV, I instead just felt angry when people would say this to me.

41. I was asked once whether I would like to see someone, as a rather matter of fact statement, meaning psychological support, counselling or therapy. I have not sought out any psychological support myself.

42. GRO-C GRO-C. In Athens, as soon as information was available, we were informed straight away, including our test results. We were sent information and then it is up to you what you do with it. This was entirely different to our experience in the United Kingdom and with the NHS where my personal information was kept hidden from me (for example, please see paragraph 45 below).

Section 7. Financial Assistance

43. I didn't receive any information about financial assistance available to assist me until near the very end of my treatment when a nurse walked me out of my appointment and told me, "you know you could go to Skipton". It was only this one HCV nurse who asked me whether I knew about the Skipton and Caxton funds. She then gave me the respective telephone numbers and address so that I could contact them. Before this I had no idea such funds even existed. My wife and I were very grateful to this nurse for telling us.

44. The process of applying to the Skipton Fund involved a lot of toing and froing due to the amount of paperwork involved. We had to first get a letter from my GP to confirm my diagnosis. As part of this process I was informed by the Royal Hospital for Sick Children, that they no longer had any of my records from the operation, as apparently the records that they held from that period were now all destroyed. I found the whole

process a fight; it was a fight prove how I contracted HCV, and a fight to access funds.

45. I was successful in my application for a Stage 1 payment from the Skipton Fund. It took three years of trying to finally succeed in obtaining the Stage 2 payment as doctors refused to provide confirmation that I had cirrhosis of the liver, with one consultant refusing to say the word cirrhosis and instead just saying that I had "badly damaged scar tissue".

46. The only reason that we were able to prove that I did in fact have cirrhosis of the liver was because GRO-C GRO-C my wife requested the hospital file. It was within this file where we found written confirmation that I had cirrhosis of the liver. This confirmation was found in a letter dated 24 June 2016 from Victoria Hospital to the GRO-C, Royal Infirmary of Edinburgh which noted "he does have cirrhosis secondary to his previous infection and will remain under ongoing follow-up". Please find this letter annexed as **Exhibit WITN042703.** It was this confirmation that I needed to be able to receive the Stage 2 payments from the Skipton Fund, now the Scottish Infected Blood Support Scheme ("SIBSS").

47. I finally received a letter confirming that my application to receive Advanced (Stage 2) HCV payments from the SIBSS was approved on 21 December 2017. This letter is attached as **Exhibit WITN042704**. This letter confirmed that I would receive a £20,000 lump sum payment and monthly payments of £2250 from the scheme on or around the 15th of each month.

48. Although the money definitely helps, the application was a drawn out and difficult process; there was a lot of disappointment and anger incurred along the way. Because I am unable to obtain life insurance due to having HCV, I am conscious of putting the funds that I receive from the SIBSS away for my children's' future.

Section 8. Other Issues

49. I don't understand why I was never contacted by the hospital where I received the transfusion in 1974. They knew that I had a blood transfusion there, and likely knew

that it was infected blood, so I cannot understand why I was never contacted or followed up by anyone from the hospital or the NHS. GRO-C

GRO-C

50. I believe that there should be routine tests for HCV, at least for people who have received blood transfusions prior to 1989. I believe that many people today will still not be aware that they have HCV until routine testing is in place.

51. I have also noticed that in many hospitals it appears to be relatively common for nurses and doctors not to be wearing gloves. On multiple occasions, my wife and I have had to ask them ourselves to wear gloves, to which they have often refused. This has been frustrating as I feel that those working in hospitals should be aware of the risks of contamination, without us having to make them aware and take it upon ourselves to ask them to wear gloves for their own safety.

52. In early 2018 I received a phone call out of the blue from Professor Goldberg, Chair of the Clinical Review of Hepatitis C Group for NHS National Services Scotland. He arranged to come and visit me at home, which he did in mid-2018. Professor Goldberg listened to my story and took my statement about my experience for his research and Report, "Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government" which includes some of my comments regarding my experience in the "Conversations" section of the Report. I received a follow up letter from Professor Goldberg, along with a copy of the Report, on 9 July 2018, please see **Exhibit WITN042705**.

Statement of Truth

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

Signed GRO-C

Dated 30/01/2020