Witness Name: Carol Craig
Statement No.: WITN3746001
Exhibits: none
Dated: 28th May 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAROL CRAIG

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27th August 2019.

I, Carol Craig, will say as follows: -

Section 1. Introduction

1. My name is Carol Craig. My date of birth is GRO-C 1951. My address is known to the inquiry. I am married to Alf Young, we married on 14th August 2006 but have been together for many years. I am essentially retired but I do work part time as the Chief Executive for The Centre for Confidence and Well-Being. I started the centre in 2005 and I still spend time keeping it going in a low-key way. We have books that we publish which I edit and I also help write blogs for the centre. I also help set up and run events for the organisation as well. I work from home when I feel I am able to. I don't get paid money for the work I do at the centre, so I still have a professional life but it's more of a low-key charitable professional life. 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.

Section 2. How Infected

2. In March 1976 I had a uterine haemorrhage which led to me being admitted to the Western Infirmary, Glasgow and receiving a blood transfusion of five or six units of blood and plasma. The doctors told me afterwards that technically I had died and they managed to revive me with the transfusion. I do not know the name of the doctor that treated me for this.

3. Recovery from the haemorrhage was slow. I felt really quite ill afterwards. When I was diagnosed in 2011, I discovered that I had a high viral load of hepatitis C. From my understanding, this is common when infected from a blood transfusion. I essentially got a huge dose of hepatitis C. It's amazing that I have managed to live with it for as long as I have without knowing until 2011.

4. No information was given to me about the risk of infection posed from receiving the blood transfusion.

5. I didn't find out I had hepatitis C until many years later in June 2011. I had started to feel really unwell, I was a bit stressed from work at the time and was not feeling great overall. My LFT test results were not within the normal range, so my GP at the Edenkiln Surgery, Strathblane, sent me for a scan to check on my liver which came back fine. But my doctor still felt that something wasn't right, and wanted to conduct further tests. I always thought that I just had a weak liver. She was the first one to really question why I had these problems. That was the first time anyone had asked questions about my liver. Over the years there were had been issues with my LFTs but they were never looked at seriously. She didn't tell me that it was a hepatitis C test but that's what she wanted to check. That was the first time I was ever tested for hepatitis C. In retrospect I am shocked by that.

6. I had quite a lot of problems with my liver over the years and had my gallbladder removed in 2001. I am surprised I was never been tested for hepatitis C then. .

7. My doctor tested me and it came back positive. My diagnosis, was a pretty unpleasant experience because when I went down to the doctor's surgery to get my results she wasn't there, it was a locum who spoke with me. She was quite aloof and unpleasant, probably because she was embarrassed at having to tell me I had hepatitis C. I was shocked by the diagnosis, I was in denial. I asked her, how I could have contracted it and she started asking me about drugs and things like that. She didn't even enquire if I had ever had a blood transfusion. It was only later that day when I was talking to my sister Janice, who is a nurse, that the 1976 blood transfusion was raised. She said to me that she had always wondered if I had been exposed as she received some training on hepatitis C in her professional life, and wondered if this accounted for my liver problems and the fact that I was the only person she knew who became very ill if I had much to drink. She had never raised the issue with me before. That is how I found out, it was really quite unpleasant.

8. I received no information from the locum when I was told. I have to say that my own doctor was very good though. She had worked down in Manchester where there was much more awareness of hepatitis C, and I think that is why she did the test. I think I still wouldn't know if it wasn't for her, but I was given no information whatsoever initially. I only got information at the follow up appointment with my GP, where a confirmatory test was done. I was still in denial about being infected at that point. I convinced myself it was a mistake, however, my GP said at the appointment there was never any doubt about my diagnosis, the test was to confirm which genotype, which was genotype 1. I was then referred to the hepatitis C clinic.

9. The thing I was really angry about and felt really traumatised by, was the realisation that I had been pregnant in 1981 and 1986 while I was infected. I

could have given the infection to my sons. I read later on that it was unlikely to be passed on in utero, but when you're pregnant or looking after your children, it's something you need to know. I feared I could have contaminated them and I was really angry that I hadn't been followed up on at an earlier date. They could have said to me, you've had a blood transfusion and should get checked for hepatitis C. Or at the very least there should have been posters up in the doctor's surgery saying, did you have a blood transfusion during this period? The fact I wasn't told those things earlier, really annoyed me.

10. I read a lot myself about the risk of cross infection. I knew I could have passed it on to my husband or to my children. So there was a period where I was very anxious because of that, GRO-C GRO-C

Section 3. Other Infections

11. I have not been infected with any other infection other than hepatitis C.

Section 4. Consent

12. I do not believe I was ever tested without my full knowledge or consent or for research purposes.. They didn't even really know this virus existed. The blood transfusion saved my life but I still feel I should have been followed up on and told that I had it.

Section 5. Impact

13. Well for me hepatitis C affected my life in two parts. One part being before I knew I had it and the other after I found out. If I look back at my health, the year I was infected in 1976, was the start of my declining, fragile health. From this point, I, I felt vulnerable. Later that same year, I developed terrible acute

appendicitis. I could have died from that. That year was the start of me being really quite fragile.

14. I had my second child in 1986. When I was pregnant with him, I developed what they thought was hepatitis A. I was jaundiced and not feeling well. The gynaecologist told me it wasn't clear it was hepatitis A, he said he thought I had non-A, non-B hepatitis. His explanation of this to me was that the medical profession did not know about it and were unable to measure it. He said that, he suspected it was 'a kind of hepatitis disease', in the blood supply, that people are getting, but that doctors were unable to officially label it so they were calling it non-A, non-B. Given that he was a gynaecologist, he did quite well in telling me that I had it. He was the first person to say to me that you might have a liver disease. He told me not to have any more children. I didn't really follow it at the time, so when they started talking about hepatitis C, I didn't know that was the same as non-A, non-B and that is what I was likely to have. He was the only doctor that said to me then that it could have been related to the blood transfusion. I tried to put it out of my mind but I was quite ill during that second pregnancy and I think that was because of hepatitis C. After that I could hardly drink alcohol without feeling really ill. When I was raising my kids my health wasn't great. I didn't feel well a lot of the time.

15. Around that time, in 1981, after my first child was born I had a lot of problems with my gallbladder. On 29th May 2001, at the Nuffield Hospital, Glasgow, I had to have my gallbladder removed because it was so infected. I didn't fit the stereotype for someone with gallbladder issues. I wasn't overweight or anything like that. I was told in the hospital that the operation would be an hour long. It ended up being four and a half hours long. The surgeon said he couldn't believe what a terrible mess it was and that I was very lucky to be alive. If I had left it another month I would have had peritonitis, my gallbladder would have burst. I have read that there could be a link between hepatitis C and gallbladder issues but I didn't know if that was true until I went to one of the Inquiry hearings in Edinburgh. I spoke to a man who had his gallbladder removed in almost exactly the same circumstances. His gallbladder was also very infected after problems with his liver. That is what made me think the

issue was related to hepatitis C, I'm convinced of it. It took me two years to fully recover from my gallbladder removal. That then left me with a lot of other problems, like having a lot of food intolerances. It's miserable to have food intolerances. My transfusion in 1976 was the beginning of a quite steep decline in my everyday health.

16. I didn't know I had hepatitis C until 2011 so it wasn't until then that I started to think about the infection mentally. When I found out, I was very anxious. I felt angry about it as well because I feel I should have been told earlier and helped to understand things better. GRO-C GRO-C I didn't have a long time to wait between finding out I was infected and receiving the treatment that cleared the virus. It was around May or June that I found out and I could see they were going to pressure me into having interferon. I didn't want to do that because I had read that interferon treatment was worse than having the virus, but I still felt pressured to do it. I then paid to go to a private liver consultant at the Spire Hospital in Edinburgh to get a second opinion on doing the interferon treatment. Much to my surprise he advised interferon was the best option. He suggested I wait until I retired and do it then because this was a very nasty virus. He said he didn't used to think hepatitis was a big problem for people but he now spends his life giving liver transplants to people with hepatitis C. That alarmed me in many ways. I think my life would have been pretty miserable if I had undergone interferon treatment.

17. I was very fortunate that in September 2012, the hepatitis C clinic at Gartnavel General Hospital got in touch with me to say that they could put me on a clinical trial for another treatment. The treatment was a combination of Asunaprevir and Daclatasvir. I qualified for it because my genotype was 1B which is less common and was doing very well in the clinical trials compared to genotype 1A. After I was selected to be part of the trial, I very quickly cleared the virus, it was only around 6 months. I was declared clear in January 2013. Even though I have been cleared of the virus, I would have appreciated if I had been offered follow up scans for my liver. My liver can be quite painful at times and ongoing checks would give me peace of mind. I know that I have a

much higher chance of contracting liver cancer due to my infection for example.

18. I decided to get my gall bladder removed at the Nuffield in Glasgow because I was feeling very ill and I knew that I might have to wait up to eighteen months for NHS treatment. The decision to go private saved my life given that the surgeon had told me that my gall bladder was so thin and infected that I would have had peritonitis within a few weeks without surgery. But I was also keen to go private as I also had been so taken aback at the state of the NHS when I had been treated in the Western Infirmary, Glasgow, for my gallstones. They couldn't even give you a towel to dry yourself and were very short staffed. I just didn't trust them to do an operation safely. We had to borrow money to pay for the private treatment but its fortunate we did. The second time I used private health care was at the Spire Hospital, Edinburgh when I had an appointment with a liver consultant. That was just for the peace of mind of having a second opinion. I felt a lot of pressure to start interferon, and it was repeatedly raised with me at every appointment.

19. I was very fortunate to have been treated on the clinical trial very soon after my diagnosis. I don't think that was an option for a lot of people, some had to wait decades knowing they had this nasty disease, or they had to go on a treatment that was terrible with very little chance of success. I was really quite fortunate.

20. My treatment was alright, there weren't many side effects or anything like that. At the end of it, my gut wasn't in great condition though. When I went back to the clinic I mentioned the problems I had with my stomach saying that I couldn't even take a painkiller. They were infectious disease specialists so they thought it might be helicobacter pylori, which causes stomach ulcers. They tested for helicobacter pylori and that is what I had. I was then given triple therapy, including two different types of antibiotics, to help clear the helicobacter. I am convinced that this treatment made my gut problems much worse.

21. There was only about a year where I knew I had the virus before it was treated. I told my dentist and doctors about my hepatitis C but I don't think I had it long enough for it to really affect my treatment for anything. My dentist just said they had to assume everyone had it anyway, in terms of how they approach patient care. I can see how for some people that the feeling of being contaminated and feeling like a threat to people would have had a huge impact on their mental health. I was very lucky that the period I was aware of my infection was short in that sense.

22. Hepatitis C really affected my digestive system. It started out that I couldn't drink milk, I became lactose intolerant even though I'm not genetically lactose intolerant. After the hepatitis C treatment I developed a number of food intolerances. That had a big impact on my social life. Going for dinner at someone's house or going out to eat became a lot harder. It's a big issue to not be able to eat the things you would like. That is one of the main ways hepatitis C has affected me.

23. My family took their cue from me on how to feel about the stigma of hepatitis C. I can understand how for some people, the stigma must be terrible, but I just decided that it wasn't my fault and if anything, it explained so much for me. I didn't embrace it as a stigma, I took it as an explanation and as something that, if dealt with, could make me feel better. I just decided I wasn't going to let the stigma affect me, I didn't keep it a secret, I told people. I was quite happy to come out as a hepatitis C victim.

24. When I had my gallbladder out, the recovery from that definitely affected my ability to work, but I was working for myself at that point, it was different than most jobs. I was a training consultant and I used to do workshops. So it affected how much I could do. Even now, I don't feel like I have wonderful health.

25. I wouldn't say that hepatitis C affected my financial situation directly but it did indirectly have an effect. I was ill continually and that stopped me from doing what I could have if I was healthy.

26. Even though it was only a short period of time that I knew I had hepatitis C, I would say it had a big impact on my elderly parents. When they found out about my diagnosis they were very shocked, it was hard for them. It was also very stressful for my husband. In the months leading up to my diagnosis, the effects of the infection were especially bad. That period had a big impact on him, he was very worried. I would say there was a period of anxiety for everyone around my diagnosis at first. Had the period between my diagnosis and treatment been longer I think it would have been awful. I was very lucky it was only for a few months.

Section 6. Treatment, Care and Support

27. No psychological support or counselling has ever been offered to me. I don't think it would have helped me personally, I've always done that sort of thing with my emotional support in my own circle. I had people I could talk to during that period, but a lot of people didn't have that and they should have. I think I should have been offered support but I wasn't.

Section 7. Financial Assistance

28. I have received money from the Skipton Fund and SIBSS. From Skipton, there was an initial payment of £20,000 in September 2011. The second payment from the Skipton Fund was £30,000 in December of 2016. I receive an annual payment from the SIBSS now which is £6,300 a year because I believe that I am moderately affected by my hepatitis C.

29. I heard about the Skipton Fund through the internet I think, it was a long time ago. I initially heard about SIBSS through the newspapers but I think they sent me a letter directly as well. I think being in receipt of monies from the Skipton Fund meant that I was in the system.

30. Applying to the Skipton Fund was quite straightforward for me. There was a record in my file, a letter, about me receiving that blood in 1976. So all I needed to do was show them the letter and I received the money. I didn't have to fight

for it or prove anything more than that. When I went to the Inquiry hearings, I could see that this wasn't true for everyone. For the SIBSS payment, I initially said when applying that I wasn't that affected. But when I told my family I had done that they couldn't believe it as they could see how having hepatitis C continued to have an effect on me. So then I went back to them and said that I was moderately affected and they were fine with that, they just said I needed a letter from my doctor to support the application. I can't fault them, they've been very good.

31. I think for the impact that the infection has on my life, it's not enough money. I don't think its proper compensation really, the amount isn't adequate. I feel that even for myself and I haven't been hugely effected. If you look at it from the point of view of the people who have been really badly affected, I think it's absolutely shocking.

Section 8. Other issues

32. The main issue for me is the lack of follow up for people the medical profession knew were at risk of infection. They knew that the chances of contaminated blood being used for transfusions during a certain period was really high. They should have followed up with people and told them.

Statement of Truth

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

Signed GRO-C
Carol Craig (Jun 10, 2020 09:42 GMT+1)

Dated Jun 10, 2020