Witness Name: Janet Johnston
Statement No.: WITN3750001
Exhibits: none
Dated: 27th June 2020

# INFECTED BLOOD INQUIRY

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## FIRST WRITTEN STATEMENT OF JANET JOHNSTON

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

I, Janet Johnston, will say as follows: -

### Section 1. Introduction

1. My name is Janet Johnston. My date of birth is GRO-C 1956 and my address is known to the inquiry. I am currently single and I have been divorced for 20 years. I have one daughter, Sharon, who is forty five. I previously worked for Shell in their filing department and have been working part-time as a counsellor since 2003. 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. In October 1983, I was suffering from kidney failure. I was very ill and needed to be taken to the Glasgow Western Infirmary because I was anaemic and required dialysis, with blood transfusions being part of that treatment. I cannot remember the exact date I was admitted to hospital. Starting in October 1983, I received a number of units of blood whilst receiving dialysis for the treatment for my kidney failure, I cannot remember exactly how many I received. I may have received units of blood up until my transplant in 1985.. My GRO-C than donated one her kidneys for my transplant. I contracted hepatitis C from receiving the blood transfusions as part of my dialysis. I do not know which batch of blood gave me hepatitis C, only that it was a result of one of the transfusions between 1983 and 1985.

4. I was given no information at all before I received the transfusion that there could be a risk of infection. All I was told was that the transfusions were necessary for my dialysis because of how poor my health was at the time. I remember looking back, lying in the hospital bed, seeing all the blood going into me and thinking this was going to make me feel better. I could not have been more wrong about that. I often wonder if the doctors really did not know that the blood was harmful, that is something I will never know for sure.

5. The blood was not mentioned again until I was phoned by my consultant, I cannot remember their name, in either late 1985 or 1986, after I had received my transplant. He asked me to come in to the Western Infirmary Glasgow as they had found an infection in my blood. At the appointment, my consultant told me, almost incidentally, "*by the way you've contracted a virus we are calling non-A non-B hepatitis*". He said they didn't know much about it and that I should just go away and forget all about it. That was all that was said, my appointment was only five or ten minutes long. I was given no information about the infection whatsoever.

6. I do not know whether I could have been told about my infection at an earlier point. That is something I have never known, whether I was told as soon as

they knew or whether my diagnosis appointment was just the date they decided to tell me. They could have known and just not said anything. It felt as if they were just trying to get my diagnosis out of the way. I was given no information at all, nothing about having any symptoms andnothing about cross infection.

7. I was given no information about the risk of cross infection. That led to a lot of anxiety and fear over having potentially infected the people in my life. To this day I do not know if I have infected anyone.. I actually started to get worried when the advice from doctors started to focus on stopping cross infection. They would warn you not to let anyone else use your tooth brush for example. Sharon had used my toothbrush numerous times over the years, if she had forgotten hers when she was staying over with me from time to time. That's when I started to get scared. I started to think about my partner as well and whether I could have infected him.

8. My infection made me feel like I was different to everybody else. The fact that I was not given enough information about my infection just made all those worries worse. Especially because I didn't have the information to pass on to my family either. I had no information about how it could be passed on, there was a time when I didn't even know it could be passed on. Looking back now, not having that information made me a liability to those close to me. I was not informed well enough to protect them. All of those feelings are still with me today.

## Section 3. Other Infections

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

## Section 4. Consent

10. Periodically, I would have my blood tested as part of my kidney dialysis treatment, every three months or so. It is possible they could have tested my

blood then but I do not know for sure. I have no idea what they were doing with my blood after it was taken from me.

11. It is possible I was tested without being given full and adequate information about what they were doing but I cannot be sure.

12. As far as I am aware, I was not tested or treated for the purposes of research, but there is no real way for me to know that for sure.

## Section 5. Impact

13. Mentally, I think the stigma affected me quite a lot. I actually used to feel dirty because of it. I used to feel that the most when I was attending the Brownlee Clinic at Gartnavel. I used to think that the student nurses there thought I was a heroin addict. I wasn't a heroin addict but I was surrounded by people that were. That was a shame for them but the difference between why they had hepatitis C and why I had hepatitis C, was that they had infected themselves by using dirty needles and I had been infected by something that was not my fault. It made me feel like a leper in a way. Even with my own friends on social occasions I would sometimes feel worried that I could pass the infection on to them. It was a fear that nagged at me a lot of the time.

14. Physically, I always remember how difficult it was for me to get up in the morning. I just felt so lethargic and drained. I did not want to do anything or talk to anyone. At the time I didn't understand it, I thought, I have had my transplant, how can I still be feeling like this. It was a real effort to do anything physical, my legs just felt like lead. I remember going to work and getting off the train at Charing Cross, the stairs there were very difficult for me. By the time I had walked to work, it felt like I had been up for a whole day. Never for a minute did I think that these feelings were physical symptoms of hepatitis C. I had this virus in my system for almost thirty years in total. For most of those years, I was left not knowing what was causing these symptoms.

15. A lot of the time I had no appetite, I couldn't even bring myself to make anything. The infection also gave me a terrible itch. I cannot remember when that started but I remember feeling like I needed to scratch all the time. I also felt like I started to bruise very easily as well.

16. When I look back, from 2001 onwards, my infection was starting to become apparent, I was probably a wreck but I thought all of those things were just normal for me.

17. In 2001, during an appointment at Stobhill Hospital, Glasgow it was mentioned to me, almost in passing that I should have my liver checked, because of the hepatitis C. That was the first time any doctor had mentioned liver damage to me, sixteen years after I had my kidney transplant. The doctor I saw that day said he was going to refer me to the Brownlee Clinic at Gartnavel Hospital. Going to that clinic was the first time I had experienced the stigma around hepatitis C. When I went there I was surrounded by drug users and I felt I was being treated the same way they were. It didn't seem to matter that I had been infected by a blood transfusion, which I felt was unfair. The doctor I saw at that clinic was the GRO-D at the clinic, a Dr GRO-D He told me very similar things I had heard at diagnosis, that it was a new virus that they were still try to understand it. But he told me that they would not be able to treat me because I had currently had a kidney transplant. He told me that the hepatitis C was damaging my liver and they wanted to perform a liver biopsy to assess the damage. The test showed that there was some damage to my liver but not a lot. I was told that day that if they had given me any treatment for the hepatitis C at that point, it was interferon that was available then, I would have lost my transplant.

18. I kept attending the Brownlee Clinic and having my liver tested as the months went on and then seventeen years after my transplant, sometime in 2002, at an appointment my daughter Sharon had come along to, Dr GRO-D asked how long I had had my transplant. I said seventeen years. His exact words were, "*Well you have had a good run at it*" He said I would be better off on dialysis

and allowing him to treat my hepatitis C with Interferon, as that would allow them to treat the hepatitis C with interferon. I could not believe what I was hearing. I remember when I got home that day, I just felt overwhelmed with despair. I could not believe the doctor had said that. That was the first time I realised that this was quite serious and it was not a case of just going away and forgetting about it like I had been told. I went on to have my transplant for another thirteen years.

19. After I was referred to the Brownlee Clinic in 2002, I kept going to the clinic and symptoms started to spring up that I know now were because of the hepatitis C. I felt lethargic and tired. I started to suffer from a lot of itchiness and bruising as well. I felt sick sometimes. It was a real trudge in the morning to get up and go to work, I felt like I was dragging my feet everywhere I went. But at the time, I just put that down to how I was feeling most of my life because of my kidneys, it was almost normal for me so I almost didn't notice that it was the hepatitis that was causing these symptoms.

20. I lost my transplant in May 2016. It had been perfectly fine for all those years and then suddenly in 2016 it failed. In 2010 my blood results took a dip and over the next five years my transplant started to fail because of that change. I do not know what caused that dip in my blood results only that it caused me to lose my transplant. It could have been because of the hepatitis C but I will never know. This meant that I had to return to dialysis. After having my transplant for so long, I couldn't face going back to a life on dialysis. There was a period after my transplant failed, where I just felt like I should be left to die. I couldn't face having to go back on dialysis, however I have learned over the years that if you change how you think, you change how you feel. That thought helped me find the strength to keep going and start dialysis again. I started my dialysis again in May 2016 at the Vale of Leven Hospital, Alexandria. Once I had restarted my dialysis, I was then told it would now be possible to treat my hepatitis C.

21. I was offered treatment for my hepatitis C around August 2016 with a new treatment from America. It was a combination of Sofosbuvir and Ribavirin and

the treatment was a twelve week course. I completed the course of treatment while I was receiving my dialysis at the Vale of Leven Hospital but I could take the pills at home. After I had completed the twelve week course they tested me and confirmed that I had cleared the virus.

22. I remember they put me in a separate room from the other dialysis patients because I had hepatitis C. I remember hearing the other patients asking why I was in a separate room from time to time. That brought back that the feeling of being different to everyone else again.

23. There were some pretty nasty side effects from the treatment. I remember I suffered badly from insomnia because of it. There was one point where barely slept for three weeks, I did not think it was even possible to go that long without sleeping before I went through it. Every week when I went to hospital, I would ask them to give me something to help me sleep. They gave me some sleeping pills after the third week of this but it did not work and I still did not manage to sleep. I just remember pacing up and down in my flat trying to get myself to a point where I could sleep but nothing worked. I would just try and find things to do like ironing or washing but you can only do that for so long. I remember praying that I would fall asleep at points. The insomnia made me question whether this treatment was going to be worth it if I couldn't get any sleep, it was extremely stressful. The problem with getting to sleep is something that has stayed with me, I still struggle with it today. It happens to me periodically, maybe three or four times a month, there are days where I know that I am not going to sleep. It will get to five o'clock in the evening and I just know that I am not going to get any sleep that night. That is something the treatment has left with me.

24. The treatment also caused me to lose my appetite again, which I think just flared up everything else. Also I had a lot of aches in my body during the treatment, they were all over my body but mainly in my joints, they made moving around quite difficult.

25. Around two months after my treatment, even though I was still on dialysis, I felt so much better. The difference was night and day for me.

26. The obstacle I had to treatment was that I had a kidney transplant, and that meant I was not able to receive treatment until 2016. I was also the first patient to receive the treatment whilst on dialysis. I think the doctors took some time to see if it would be appropriate for me because they were not sure how the treatment would respond to someone on dialysis. They gave me the treatment as soon as they knew it would be okay, it was only a slight delay. It was decided that the best solution, was for me to take the pills after I had finished my dialysis for the day. I think the reasoning was that it was better to take it after my dialysis as opposed to taking it and then having my blood cleaned for a number of hours. They did say to me that the treatment had been shown to be very effective but they were not sure how effective it was going to be for someone on dialysis beforehand. Luckily the treatment was successful and I cleared the virus despite being on dialysis.

27. The only impact my infection has had on other treatments in my life was during a time I lived in Manchester in the 1990s. I went to a dentist there but they did not have my medical notes, so I had to tell them that I had hepatitis C. At that point I didn't know there was any risk from having hepatitis C. That dentist refused to treat me because of it. Other than that one incident, my infection has not impacted my treatment for anything else medical or dental.

28. I think socially I was always worried about the stigma of hepatitis C. When I was out with my friends, I didn't know how much they knew about the infection. I had told my friends about my hepatitis and that I had been told to go away and forget about it, but I never knew what they thought about that in their own minds. That was something I thought about a great deal.

29. I also worried about my family and about the risk I posed to them by not knowing enough about the infection. Looking back, when my daughter Sharon was living with me, there were so many things that could have caused a risk

of cross infection but I just did not know at the time. I still think about that even today. With my ex-husband, because I did not know enough about stopping the spread of the infection, we weren't taking any precautions when we had sex. I don't know if there was any blood passed to him, there could have been. There is no way for me to know that and I was not given enough information to stop that risk with the people in my life. There are so many people I have been in contact with over the years that I could have passed the virus on to in one way or another. The lack of information I was given, means that I honestly cannot say whether I have passed the infection on to someone, even today. I think it was pretty unprofessional for the hospital to just tell me go away and forget about it because that has put so many people in my life at risk.

30. Sharon has felt some of the impact from the stigma surrounding hepatitis C. She was with me at the appointment when I was advised to back on dialysis in order to start treatment for hepatitis C. That was the first time she saw how other people talked about it. I think that really made clear to her how bad people thought it was. I was always scared to tell her about the risk of cross infection from using my toothbrush from time to time, because I didn't want her to worry about it. I didn't want her to panic about having the infection as well.

31. I tried not to take days off from work because of my infection but there were days where I just had to. I would phone in sick and say that I had a cold when really I just needed rest, I was absolutely exhausted. I would spend those days asleep in bed because of how fatigued I was. I felt like I could not phone and tell them the truth, that I was exhausted and would not be able to work.

32. Apart from having to take the odd day off from exhaustion or for my dialysis there was not a big financial effect from my infection because I was still managing to go to work. I did not know that financial assistance was available, if I had known that, things might have been better for me.

33. I think when my family and my ex-husband found out about my infection initially, they were in the same boat as me, completely oblivious to the

seriousness of the infection. I was not given enough information for them to understand what it all meant. Sharon is the person who is closest to me in the family and I think it scared her when we found out how serious the infection was further down the line. She wouldn't have said anything to me directly but I know she would have gone away and worried about it when she was alone.

## **Section 6. Treatment, Care and Support**

34. I have never been offered psychological support or counselling because of my infection, it was never even suggested. I think that kind of thing would have been invaluable to me, it would have helped me work through so many of the issues I dealt with on my own.

35. I actually completed a counselling diploma myself. I did a two year psychodynamic diploma, starting in 2003, at the Garnethill Centre, Glasgow. I had always been good with people and listening to them and it was something I found I was quite interested in doing myself. I also had a lot of feelings that I wanted to know how to deal with, the feeling of being different and of being dirty inside. As part of the diploma course, you had to have your own therapy. So unintentionally, I had almost two years of therapy. It was the best thing I have ever done. During those two years of therapy I was able to bring everything I was feeling to the surface and properly deal with it. Looking back now, I can see that I was just ignoring everything. I was ignoring my fears about it, I was ignoring the symptoms themselves and I was ignoring how I felt about it all. One thing that came out during the therapy was how abandoned and dismissed I felt about having hepatitis C, and how I was shooed away by doctors about it. For such a long time I did not understand why I felt different to everybody else and the therapy really helped me work through all that. But no medical professional ever suggested that counselling could help me. It was something I had to pursue on my own which is a shame because I know first-hand what an immense help it can be.

## Section 7. Financial Assistance

36. I have received a payment of £20,000 from the Skipton Fund. I think I received that in either 2000 or 2001. I found out about the Skipton Fund by overhearing a chance conversation in the Brownlee clinic. There was one day I was sitting in the waiting room at the clinic and I overheard two men, two drug addicts, talking about the Skipton Fund. I heard them talking about how the fund could give you money if you had hepatitis C. It doesn't sound real, but that is how I found out that the fund existed. I wondered why no one had told me about it for all these years. A couple of months later I looked it up online and learned all about it and took the form in the next time I went in to the clinic. There was a section on the form for my doctor to confirm that I still had hepatitis C and I got him to fill it out for me. He had to do a blood test to confirm my infected status as far as I can remember, but once that was confirmed he signed off on my application. It was a complete stroke of luck that I heard about the fund at all. I would say the process of applying to the Skipton Fund was very straightforward. After I had sent the application off, it was only a few weeks before I received the cheque in the post.

37. I also received £166 a month for twelve months from the Caxton Fund starting sometime in 2016. I was also able to access a grant for a new boiler through the Caxton Fund. All I had to do was send them a few estimates for the cost of a new boiler and a few weeks later I received a cheque for it. I found out about the Caxton Fund after a friend of mine had searched online for financial assistance for hepatitis C for me and found the Caxton Fund website. Applying to the fund was quite easy. When I looked on their website, they asked you to enter your registration number from the Skipton Fund, if you had one, and they would send the application form to you. The application asked me for some information about my medical history and finances at the time. The Caxton Fund was also very straightforward to deal with.

38. I receive £525 a month from the SIBSS and started receiving that in April 2019. I also received a payment of £30,000 from SIBSS around three years ago. I discovered the SIBSS after receiving a letter telling me that the Caxton Fund

would now become the SIBSS. The letter happened to explain that the SIBSS could provide financial assistance for things like gas bills. After getting in touch about this gas bill assistance, I found out I was eligible for it. I received a cheque for £1,000 to help me with my gas bills and I received that around two years ago. Applying for payments through the SIBSS was fairly simple but I did have some issues with their self-assessment form in September 2018, when they switched to the self-assessment method. I was sent out the self-assessment form but I thought it did not apply to me at that point, because I no longer had hepatitis C. I actually threw the form away. I happened to phone SIBSS about 5 months later to ask a question about the gas bill payment and the women I spoke to asked if I had received my self-assessment application form. I told her I had but that I did not think I would be eligible. She explained that I was. She said it did not matter that I had cleared the virus and that I would still be entitled to a monthly payment, With that confusion out of the way, I received another form and filled it out. It asked me for some information about my infection, my medical history and my current financial circumstances. Two weeks later I started receiving my £525 a month payment. The SIBSS have always been easy to deal with.

39. My own experiences make me wonder how many other people out there, might not know this financial assistance is available. For me, if I had not overheard those two men in the waiting room, I may have never have known. I would not have heard about the Caxton Fund either if it hadn't been for my friend looking into it for me. There must be so many people who have not received any financial assistance simply because they don't know it is there. I cannot understand why it is not advertised.

40. I cannot fault the funds myself, they have been of such a great help to me. They have all been really helpful whenever I have had to phone them for anything.

## Section 8. Other Issues

40. I have nothing else to bring to the Inquiry's attention.

## Statement of Truth

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

Signed GRO-C
Janet johnston (Jun 30, 2020 10:39 GMT+1)

Dated Jun 30, 2020