



CF/V1850199

Witness Name: Gillian Hazelton

Statement No.: WITN2157001

Exhibits: **WITN2157001**

Dated: 14th December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GILLIAN HAZELTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, Gillian Hazelton, will say as follows: -

Section 1. Introduction

1. My name is Gillian Hazelton. My date of birth is GRO-C 1949. My address is known to the Inquiry. I'm currently retired but prior to this I was an English and guidance teacher. I am currently married to my husband Gerry Hazelton. Gerry was a solicitor but has since retired. I intend to speak about my infection of Hepatitis C through a blood transfusion. 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

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2. I had twin boys, Gerard (Junior) and Lewis, who were born on [GRO-C] 1982. On [GRO-C] of that same year I passed a huge clot and was sick and dizzy. I was sent home from the hospital on [GRO-C] 1982. On [GRO-C] [GRO-C] a midwife was visiting the home and thought I was losing too much blood. The next day on [GRO-C] I was sent back in to hospital. On the [GRO-C] [GRO-C] I was taken to theatre and haemorrhaged while in theatre and that is when I was given some blood. On [GRO-C] my temperature was up to 103 degrees and I believe I received a transfusion of around 2 pints of blood. On the [GRO-C] 1982, more blood was given and I was on an all day and I do not know what was in the drip. On the [GRO-C], my temperature was up to 104 and I was given more antibiotics. I was told that I had septicaemia. On the [GRO-C] my blood count was now at 8. On the [GRO-C], I was sent home having went down to 9 stone and 2 pounds. I was very depressed at this time. On the [GRO-C] my own doctor, Dr Shaw, came to my house and was there for one and a half hours. On the [GRO-C] 1982, there was blood in my urine and I was down to 9 stone. On the [GRO-C] I suffered from rigours and my temperature was then up to 105 degrees and I was taken back into hospital. On [GRO-C] I had more rigours and my temperature was up to 105 still. My blood count was at 10 and I was suffering from a heavy green vaginal discharge. On [GRO-C] my consultant Dr Chatfield, said he thought all infections were gone. I was sent home on the [GRO-C] 1982. Photos from around this period and for some time after, show me as yellow. I did not notice this at the time but it is something I can see when I look at the pictures now. This is only time in my life that I have received any blood transfusion. Dr Chatfield was my main consultant while I was pregnant. He was a lovely guy and came in to check on me every day and he was very caring.
3. I am not aware of ever having been told that there was any risk about having a blood transfusion. I was in theatre when my first transfusion was given, so I could not have been asked, as I was unconscious. My husband was not present when I was told about having more transfusions beyond the first.

4. On 25th January 1999, I received a letter from the blood donor service and this stated that they had detected a liver virus in my blood donation and I was called in to go see them at West Regent Street. I was asked a lot of questions there about my sex life and what happened when my children were born or if I had taken any drugs. I eventually asked what was wrong. They told me that I had hepatitis C and that I must have got it from the transfusions I had received when my twins were born. Following this, I was referred to a Dr Mills at Gartnavel hospital. I found after some blood tests that I had active hepatitis C and my own immune system had not killed it.
5. Lots of visits to Gartnavel ensued and I wanted to go on trials for treatment but my own immune system was too low to cope with this. The trial itself showed that ribavirin alone did not work. Time passed and the treatment changed to ribavirin and PEGylated interferon. I had genotype 4 Hepatitis C and they told me this would take one year to treat.
6. I did not see any particular doctors around the time that I now realise I looked a little jaundiced. No one seemed to connect my slightly yellow complexion to the blood transfusion as contaminated blood would not have been known at the time. My own Dr Shaw, who I had mentioned, has now retired and he was based 10 Queen's Crescent.
7. When I went in to the blood donation service near West Regent Street, I went in by myself because I did not think whatever it was would be a big deal. As soon as I went in, I knew something was wrong as a doctor, or at least a man and nurse, came into the room. I do not know either of their names. I believe the man was a doctor. They did not tell me immediately what was wrong and they asked about my medical health and the other questions I have already mentioned in terms of my sex life and any drugs and things like that. When they told me that I had contracted hepatitis C, I had never heard of it before, although I knew of A and B.
8. I asked them how I could have got that. They said straightway that it was through transfusions. While the questions they asked me were quite

uncomfortable, I can see why they asked me what they did. They asked me if I had taken any drugs or slept with any drug takers, which I responded to with a clear "no". It was after that that they told me about the virus.

9. In terms of the advice that they gave me, they told me that I was now uninsurable and that there was no cure. They advised me not to tell anyone and there was a stigma due to the fact that it was predominantly drug takers who had hepatitis C. I was so shocked. And when I went to my own doctor and told him, he knew very little about it. My own Dr Shaw, when I told him, phoned Dr Mills who is the head of haematology at Gartnavel hospital, and an appointment was made straightaway.

10. I do not believe that I was given any advice about managing the infection. They did ask how I was and asked if I had been extra tired. I told them that 20 years ago, I had twins, and had been very ill and I had been looking after the twins so tiredness had sort of become the normal at that point. I went back to work after maternity leave.

11. In retrospect, I do believe I did have had flulike symptoms. I had aches and pains but I put this down to just having had two children at once. I think I may have been a little more irritable at times. My own work was also stressful as I was holding a high-level post.

12. My son Lewis is a dentist and it was not long after he went into dentistry that I found out about having hepatitis C. GRO-C
GRO-C

13. GRO-C

14. My husband did not want to be tested because if he was found to have hepatitis C then he would be uninsurable too. We've been living together for 20 years, over the time between the birth of my sons and when I was

diagnosed.

GRO-C

GRO-C

15. In terms of if the information I was given was adequate, I think they gave as much as you could really retain at that point. It was Dr Mills at Gartnavel hospital who told me more than the people at the blood transfusion service. I think they were measured on how much they thought I could absorb. Dr Mill's advised to see what genotype of hepatitis I had, as well as what viral count or level I had. I had a liver biopsy just after my diagnosis. I believe that those results said that I had very mild cirrhosis of the liver. They did say that there was a caveat at this point, and said that they had taken a small section of my liver and therefore could only assess any damage from that particular area. I was told what alcohol levels I could have and to eat a healthy diet. I believe it was Dr Mills and a practice nurse that I saw around this time, although I cannot remember her name. I do not believe that the information could really have been provided to me earlier.
16. My main view is about how the results were communicated to me are that I do think on the day that I got told, I went in by myself. I think they could have shown more concerned about how I was, as it was such a shock and I felt very abandoned. There was a general feeling of 'now what?' I think they should have done more than said to go to my doctor. I think they should have offered a follow-up and I felt that they had failed in their duty of care in this area. I felt it was lacking. I don't know if maybe they just thought I was all right. I'm sure they asked if I was all right and I may have said I was. I went back into the school where I worked on that very same day. At the time I was working at Bishopbriggs High.
17. In terms of any cross contamination, I'm sure they told me not to share toothbrushes. I was worried that we might have done in the past. I believe the advice about the cross contamination may have been from the blood transfusion service but I'm not absolutely sure. I think I asked either the blood transfusion service or Dr Mills if I could have infected my children and they told me that this was highly unlikely. I think at the time, I believe that

their knowledge of transference had improved in the years since I was infected and was better by the time that I was diagnosed. I think that the information given about cross contamination was adequate at the time.

Section 3. Other Infections

18. I was infected only with hepatitis C.

Section 4. Consent

19. I believe when I was asking to have a second biopsy and they asked would I mind if part of the second sample was used for research. I was very keen to do that at the time.

Section 5. Impact

20. I initially volunteered for a pilot for one of the first ways of treating Hepatitis C. I believe that there were the trials for Ribavirin but I did not get onto it. They said that my blood and white cell count was too low. I was keen for the research part of it but I was put in the control group. It was supposed to blind but as I said, I could not have the treatment because my blood cell count was too low. I believe this would have been around 2002 or 2003. I believe that they had discovered that Ribavirin did not work for my any of the genotypes. A nurse, named Sister Spence, told me that there was a new treatment of Ribavirin with PEGylated Interferon. They said that they had had good results for this.

21. I had to wait for around about a year because of the financial aspect of getting on this treatment. I believe I was on a waiting list. I believe at the time there was a big push to treat drug addicts who had hepatitis C. This annoyed me since I had got Hepatitis C from transfusions and I had not done this to myself.

22. I was very embarrassed by my diagnosis. I felt at work if people knew they might throw Domestos at me or object to me being a teacher. I felt unclean. I recall at one stage some parents came in with their first year child who had leukaemia and he had hepatitis C and I felt I could relate to them but could not tell them that I too had the virus. I did tell the head teacher at the school straightway when I found out about having Hepatitis C. I gave him permission to tell anyone that he thought should know and I believe he only told deputies in the school.

23. I believe that my ability to be there and to function as a parent was affected by my condition. GRO-C,

GRO-C

24. When I finally found out that I had Hepatitis C, I told my children. Lewis was fine when he was told about my diagnosis. Ged asked if he would have it. I did not tell my husband's family due to the lack of knowledge that they may have had and this may have meant they were nice to my face but not nice behind my back. I believe I told my husband first of all.

25. I eventually did have to tell my husband's family when I went on treatment due to the symptoms I might have faced. Upon my diagnosis, I would say I did not have any physical reaction but mentally I was just sort of accepting it at first. When treatment was mentioned, I just wanted to get onto it and the year of waiting on being given treatment was awful. I have been told that I should get this done when I was in my 50s as the chances of clearing the virus was greater. Genotype 4 that I had, had a 40% chance of being cleared. I was very aware of time passing and my age. I was not getting any younger and I was afraid that I would ultimately be refused treatment.

26. In terms of any health issues that have arisen as a result of my hepatitis, I would say that the liver issues were the only ones I was aware of at the time. As I said I had mild cirrhosis of the liver. I gave up drinking for a year completely before treatment. I believe they said that drinking could affect the treatment and I didn't want to risk any effect on it at all. I now know that Interferon can cause depression and this is what happened to me.

27. In terms of any obstacle to receiving treatment, I would say just being on the waiting list because of the cost of this treatment to the NHS was difficult. I had to wait until the next lot of funding came in.

28. I do not believe there were any other treatments that ought to have been made available to me that I did not receive. However, my white cell count dipped drastically during treatment. I was told that cancer patients received treatment when this happened to them. My interferon injections were reduced by 20%. This potentially would impact on the efficacy of the treatment and I had a 40% chance of success on the full dosage. This made me very upset. Once again it was financial decision on the part of the NHS.

29. The symptoms of the treatment came on very quickly. I suffered from the following symptoms:

- Nausea
- Tiredness
- Ulcers on my lips and in my mouth
- Mind fogging
- Hearing distortion
- Depression
- Aches and pains
- Hair loss
- Mood changes
- Taste disturbance
- Thyroid function permanently impaired
- Rosacea

Some consultant said the hepatitis C treatment was a "piece of cake" but it was horrendous. I worked for five months of the treatment and

eventually went to see a deputy who listened to the fact I was struggling. Her name was Ruth Blaikie. I got her to contact HR who came in and I was asked how I felt and she asked how did my body feel and I said my "body was screaming" and she said to go home. I couldn't even go up the stairs because I was losing my breath. Because of my white cell count being low, they had to reduce my dosage and I really didn't want them to. I remember that I cried about them lowering the dosage because I worried that would lower the chance of it working.

30. There was an itch that came with the treatment; I believe it was called formication. It was as if there were ants under your skin at all times, it was constant. People say don't scratch but there is no way you can't scratch with that. At one point the doctors looked at my back, which had erupted, and suspected lupus, but it was drug related eczema. I remember when my skin began to react, I thought it would stop after the treatment but I probably had 18 months of symptoms so it did extend beyond the treatment. You just keep going with it because you want rid of the virus. I know a lot of people gave up during the treatment and I can fully understand why. I just wanted to be rid of it. I remember one point, my face started to swell and I was getting hard lumps. My thyroid has also begun to fail and I have been put on thyroxine for this. This is a pill that I require to take for the rest of my life.

31. Sister Spence showed me how to inject the Ribavirin and PEGylated Interferon. They tell you not to inject it in the same place. Because of the brain fog I experienced, I had to make a diagram to remember where to inject myself and where I had injected myself previously. My son Lewis, who is now a dentist, helped a lot with that. I had to inject Interferon twice a week and take Ribavirin tablets every day.

32. Initially, I was dealt with by Dr Mills at Gartnavel for my initial treatment. After four months of treatment, they do test to see if the level of hepatitis C is going down. Treatment is stopped if the viral levels do not go down at this

stage. They took blood throughout and at the end of my treatment. They took some blood, 6 months later as well.

33. I remember sitting with my husband in the hospital at the end of my year's treatment and we were talking about the symptoms I had experienced and I said I didn't think I had had depression so at least had I avoided that. My husband said that I had been depressed for months. I had not realised I was depressed because I had so many physical side effects to deal with and thought I was struggling because of these. There were so many side-effects and now thinking back, I must have been depressed. The day I got my results, I expected to go out dancing thinking that I had cleared myself of hepatitis C. In fact, I felt deflated and a friend said it is like having your strings cut off. I felt their duty of care should have extended beyond this.

34. I began to hear that some people were told they were cured but they weren't. I asked GRO-D on the last day "You have used the word 'cured'. Is that correct?" and he said yes. I asked my son Lewis and he said, "The ability to detect the virus can only go down to a certain point – after that, it is undetectable. However this does not mean it has gone. They hope , your immune system will deal with any remaining traces of the virus". Yet, they knew my immune system was not good so they should have checked again over the years. I have only heard of a lot of these things through the Scottish Infected Blood Forum. I found out things that really didn't sit well with me about how others were treated. I heard of people being experimented on and of conspiracies. I still don't think that anyone really conspired to hurt me. I believe that some of the haemophiliacs in the group feel that they were experimented on and hurt intentionally and they were quite vociferous in their anger about it. I left the committee last year and had been on it for four or five years. It was founded to help people like me and at first it was supportive but in the end I did have to leave it. The stress and increasing depression meant I was unable to continue.

35. In terms of support, I recall being told by a nurse at the hospital to write to the British liver trust. I contacted the named person who was a member of

the Haemophilia Group. He was very helpful. He broke away from Haemophilia Group and along with a few others started the Scottish Infected Blood Forum (SIBF). In many ways I did not feel the membership of SIBF helped me but it kept me informed and at least I was helping others..

36. At the time of my diagnosis there was no counselling offered. When I was on treatment, they did say that they could put me in touch with someone but this was never anything clear.

37. When I was filling out my application for the Scottish Infected Blood Support Scheme (SIBSS), the administrator Sally Richards' application stated that we could receive any guidance or support if we were interested in this. She sent an e-mail with links to different Professional Therapy Groups and no clear direction. This was very inadequate. I appreciate that there are financial constraints but I generally felt very left a drift by this. When I submitted my application form to SIBSS for additional financial support, I said I wished for psychological support as well.

38. I went to my GP three years ago of my own volition because I was waking up with pains. I thought it was angina. I felt rung out. I was referred to the Western Infirmary and given a running test, which I "passed".

39. The doctor at the hospital said that no cardiovascular issues were present. He said it may be anxiety attacks and these did increase over time. This is not something I ever had prior to having hepatitis C. I recall a time babysitting for my nine month old grandson. One night I really did struggle and told my son that I thought I was deeply depressed and I burst into tears. Thankfully, Lewis was there as well as my other son and his then fiancée. They wanted to send me to Harley Street to try and get some support for how I was feeling at that point but I did not want to expend that kind of money. I went to my GP the following week, Dr Boyle, who is now retired. She asked if I wanted tablets or counselling and I told her I did not want tablets. I chose counselling. I was sent to a mental health unit in Kirkintilloch. I remember the counsellor did not tell me anything beyond her first name. I

believe talking to a counsellor there made me aware that I was doing too much at that time. I was told I had to learn how to say no. I don't know if interferon caused this because there was no mention of my serotonin levels.

40. I believe the lack of support may be down to financial constraints. I had been informed by Tommy Leggett (SIBF Manager) who said that there was only enough money for support for haemophiliacs. They said there was only enough money for them. This was with regards to psychological help for people who still suffered symptoms after treatment.

41. In terms of how my status of having hepatitis C has affected other medical treatments, I would say that I don't think it has affected how the doctors have treated me for the most part. Now I am being properly treated for my depression, but it still shocks me that no checks are or were being made when it was realised that Interferon causes depression in some people.

42. After my son's wedding, which I found at times very stressful, it was all over my husband and I went out biking and when I was on the bike I had a massive panic attack. I lay on the ground for 30 minutes and I felt as if I had regressed. I had not had a panic attack for some time and the strain of the wedding caused a huge one.

43. I felt as if I disappeared after my treatment. I used to be the life and soul of the party in the past and now I hate parties. I'll be going to one the week after I'm giving this statement and I'm dreading it already. I feel that I get anxious surrounded by large groups. When at dinner with my husband one night I said I had lost some of my social skills. I feel I don't know how to navigate social situations as well as I once would have.

44. I feel that sometimes there are too many negative aspects in my life because of the impacts of the virus. Looking after my grandchildren shouldn't be hard and I know I should be the fun gran, but my sadness stops me.

45. My work as a teacher was my salvation while everything was going on. I could be 'daft' without losing control of the class and it was an escape from my own situation.
46. The treatment and the past five or six years have been very hard for my husband. I think my expectations of his understanding at times may have been too much. We were never near divorce, I didn't really tell him about some the depressive symptoms I was having until we got back from London when I had broken down and told my son that I was depressed. I got the train back to Glasgow and I went to the caravan in St Andrews that we had, I wanted to talk to him and he thought I wanted a divorce and was relieved that that was not what the problem was. My husband has not always been understanding but he has stuck by me through all of this and he is very angry at what has happened to me. I did put my name down as a core participant and I was interviewed and gave a big statement in Edinburgh but I didn't feel anything really happened with that.
47. I do not feel the stigma so much now since I have been cleared. I feel that society has become more informed about Hepatitis C.
48. I do not believe that my diagnosis had any effect on the children's education.
49. I feel that my ambition to progress my career was stifled by my condition. I worked at Bishopbriggs High School. I spoke to the Head Teacher, Gordon Mouldsdales, when our school amalgamated with another. Each promoted teacher had to go head to head with their counterpart, in the other school. I told Gordon that I was incapable of participating in an interview due to mind fogging. So I had to resign from the Guidance role I had, but remain solely as an English teacher. He understood this. I resigned from the guidance role in 2006. This meant a potential salary dip as I went back to purely being a teacher. I retained my salary for three years. However, my career was stifled by my resignation from the Guidance role. I retired seven years ago. However, I went back as a long-term supply teacher as an English teacher from time to time.

50. I do not believe that there have been any great financial effects other than perhaps our electricity bills going up because I feel the cold more now.

51. In the past years, the last 10 especially, I have become increasingly unwell and I feel that the hepatitis C and the interferon treatment has had a profoundly detrimental effect on both my mental and physical health.

52. For years after, I feel as if I have "disappeared", become disembodied and increasingly depressed and suffering from mental fatigue. It is a constant daily battle for me. Indeed, physical side effects have manifested themselves as well.

53. In 2015 I had what I can only describe as a breakdown. I went to my doctor, and was given the option of counselling, tablets or a combination of both. I chose counselling since I did not want to go on any more medication after my interferon treatment. I also told my doctor that I had tremors in my head and that my family and friends had noticed this. These have increased dramatically, and socially this has made life even more difficult for me, and since my treatment I have been left with brain-fog where I suffer from memory problems.

54. Around the same time I was being awakened by sharp pains in my chest which soared through my chest and through my teeth, lasting about twenty minutes or so. They are very painful and leave me totally drained for about 24 hours after. I went to a locum doctor who sent me to the former Western Hospital in Glasgow for tests. I was tested for angina but I was told that they were anxiety attacks. I did not understand how I could have anxiety during my sleep but was informed by the consultant at the hospital that this often happens. These anxiety attacks now happen during the day but less frequently than during the night. This has a truly physical and mental impact.

55. This is also the case with the effect on my endocrine system. My thyroid was permanently damaged by treatment (what they call 'side-effect' of

treatment) and I am on thyroxin for the rest of my life. I continually feel cold and tired. I do exercise regularly and eat a well-balanced diet in order to maintain a slim and healthy body but it does enhance the tiredness. In addition, I have a high level of insomnia and am often irritable and desolate. This of course has an effect on my family.

56. Due to the profound mental health impacts I have and am experiencing, I have changed from being a sociable, gregarious person to one who finds any social gatherings almost intolerable. I do try to cover this up and employ strategies to help {suggested by my counsellor} but often they don't. This is happening more increasingly often and is a constant daily battle for me.

57. I was a good and popular teacher both with staff and pupils. I was a Principal Teacher of Guidance and English teacher; both demanding roles. After my treatment for hep C, the school I worked for, amalgamated with another and promoted staff such as my-self were required go head to head with their counterpart from the other school, for our job. There was no way I could tackle this task and be up to speed on new methodologies because of brain-fog. So I had no other option but to resign my post as PT Guidance but remained in the school teaching English. This meant that my career path was impeded and I had to give up something which I loved.

58. Due to my deteriorating mental health I had to retire early at 63 but almost immediately was asked to return to the school as long term supply on a regular basis. But I had my breakdown in 2015 and as time passed, I was really struggling. At one time I had to get a colleague to come to my class room because I was starting a panic attack. The school was very supportive and reduced my timetable because they wanted me to stay but eventually I could not go on and had to stop in 2016.

Section 6. Treatment/Care/Support

59. I believe at one point, I was sent to place called "At Sea". It was across from the Kings Theatre. Everyone who went there was a drug addict and I really

felt sorry for them but they did do that to themselves. I do not recall there being any support groups I could go to which dealt with people who had received Hepatitis C through NHS treatment.

60. When I was sorting out my application for the Scottish Infected Blood Support Scheme, I saw that they mentioned support so I indicated that I would be interested in getting some support, given what I have gone through. This turned out to be a list that was e-mailed to me, which included a number of different Professional Therapies, many of which would not have been suitable. This was not helpful.

61. At no time when I went to the doctor's or at counselling was the connection made to the devastating effects that interferon has had on those who had treatment. My type of Hepatitis C, genotype 4, required one year of treatment and so I was on it for a long time. Indeed I only had the connection confirmed relatively recently. Currently none of the doctors at the practice which I attend know me at all, due to constant changes in personnel within the Practice.

Section 7. Financial Assistance

62. I believe I got payments from Skipton in 2 lots. There was a payment of £20,000 but I cannot remember when. There was another payment of £30,000 which I believe was in the last year so but I do not know exactly when. I believe I likely found out about Skipton through Scottish Infected Blood Forum. I recall it being easy to apply for and all I had to do was fill out a form and send it off. As far as I know, this never required my medical records or anything like that. I sent the form and they got back to me. There were no preconditions applied to this money and how it was to be spent.

63. I did not receive anything from Caxton fund as I do not believe I was eligible to receive anything. I never really looked into it or investigated it when I heard that I would not be eligible for it.

64. I thought that what was offered was sufficient for me and we were grateful for it. I know others have had to wait years for money. I was just grateful that it was being recognised.

Section 8. Other Issues

65. I believe that it was a nurse who mentioned Frank McGuire and I came to Thompsons to see about claim. No claim was ever pursued, I believe it was a group complaint but I don't believe it ever actually went anywhere. I believe this was pre-Penrose and Thompsons were starting to look at prosecutions or offer some other sort of legal outcome but there was no outcome from this that I am aware of. Thompsons were very good keeping us up-to-date. I think I gave £200 towards this but I was reimbursed most of it by the end.

66.

GRO-C

67.

GRO-C

GRO-C

68 [GRO-C] I had a prolapse. The weight of the twins in my womb, affected my pelvic floor and it now came down. This again is not directly connected to Hepatitis C. I was in hospital at The Samaritans, under Dr Chatfield, for 10 days and in recovery for 8 weeks. My lovely mother-in-law, my husband and my friends all took it in turns to look after my twins. My friends were wonderful. They had young toddlers themselves but they looked after my children. At that time, my husband took over sole care of the boys from the time he got home from work to the following morning on his own.

Statement of Truth

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

Signed

GRO-C

Dated 27/3/19