

Witness Name: Rosaleen Bearman

Statement No: WITN44210001

Exhibits: Nil

Dated: 2<sup>nd</sup> October 2020

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF ROSALEEN BEARMAN**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 01 July 2020.

I, Rosaleen Bearman, will say as follows: -

#### **Section 1. Introduction**

1. My name is Rosaleen Bearman. My date of birth is GRO-C 1957 and my address is GRO-C Middlesex, GRO-C I live with my husband David and we have been married since 1976. We have one daughter, Rebecca, who was born in 1987.
2. I used to be the South West trainer for Clinique cosmetics, but I stopped working there in the mid 1980s because of my health conditions. More recently, I started volunteering at a local hospice charity shop. I am now employed for 10 hours a week.
3. I intend to speak about my infection with the Hepatitis C virus (HCV), which I believe I contracted as a result of being given blood and blood products in the 1980s.

4. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it had on my life.
5. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

## **Section 2. How Infected**

6. I remember being the sickly child out of my siblings and was always thin and pale.
7. In 1981, at the age of 24 I was diagnosed with an auto immune disease called Systemic Lupus Erythematosus (SLE). The disease would cause my immune system to attack my body and trigger a flare up. I suffered with the disease for 9 months before I was diagnosed. Medical professionals often thought that I was a hypochondriac because I would complain about pain all over my body.
8. At times the pain was so bad I could not even get out of bed. David would leave the front door unlocked when he went off to work, so that my mother could come in to look after me.
9. On one occasion, I was so ill that she put a mattress in the back of her estate car and drove me back to her house. I was taken to see the doctor and I remember children in the waiting room hiding behind their mothers. I must have looked like a skeleton because I had lost so much weight.
10. My doctor took various blood tests and I was sent back to my parent's house. That evening my doctor went to dinner with Dr Hughes from Hammersmith Hospital. My doctor mentioned how I had a rash over my face and had all of the symptoms of arthritis. Dr Hughes said it sounds like lupus. The doctor phoned my mother and made a referral to Hammersmith Hospital. I had an appointment on the 1 May 1981 and further tests were carried out. I was diagnosed with lupus.
11. Not much was known about the disease at this point, so I was just put onto steroids. I went from 7 to 11 stone in a month.

12. I had a number of miscarriages because of the lupus and my daughter was a twin, but I lost the other child. I was not able to have any other children after the birth of my daughter.
13. I went to the Hammersmith Hospital for regular monitoring and blood tests. When I had a bad flare of lupus, I was given blood and blood products. I remember being given immunoglobulin (human anti bodies) – it was stored in a bottle and administered via drip. I was told that it cost £1000 per treatment. At times I also required a plasma or blood exchange.
14. On 8 occasions throughout the 1980s and 90s I received blood or blood products and I think I received blood when I gave birth to my daughter in 1987. I remember the blood and blood products being administered – the blood would run down into a round filter on my chest and then into my arm. I was always told my medical professionals that the blood was safe because it was filtered.
15. One time when I received blood, the male nurse could not find a filter. He went on to remark that they were crap and did not do anything anyway.
16. In the 1990s my creatinine level was increasing and my kidneys started to fail, so I was transferred to the renal department at Hammersmith. I was told that I had lupus scars with infection and this had caused cysts to develop on the kidneys.
17. In 1997 I got an infection and my kidneys shut down altogether, so I was put on dialysis for 6 weeks and had to attend every other day.
18. I remember having a red file to indicate that I was on dialysis, but went back down to an orange file once I finished the 6 weeks. People commented that they had never seen someone come off dialysis.
19. When I next returned to the clinic at Hammersmith, my renal consultant told me that I was HCV positive. As far as I was concerned they were just running tests to check my blood, so I was shocked to be told that I had contracted the virus.
20. I do not remember how the consultant delivered the diagnosis, because I was in complete shock. I thought HCV was a sexually transmitted disease. I do not think I asked him any questions, because I thought my husband must have been

unfaithful. I kept thinking he would have to contact the person he had been with to let them know.

21. I felt very dirty and thought I already had enough medical conditions to deal with. I was asked about drug use and if my husband had ever used intravenous drugs. The consultant knew that I was not a drug user and that I had been faithful to my husband, so it was hard to be asked these questions. I was brought up by GRO-C parents, so I was not allowed boyfriends.
22. The consultant told me not to share a toothbrush with my husband and to use a condom to prevent transmission of the virus.
23. He never mentioned any treatment available and commented that 'I had to die from something', so I thought the virus was incurable.
24. In my head, I thought the cause of infection was the dialysis machine. I had no idea that I could have been infected in the 1980s when I received a lot of blood and blood products.
25. I told the consultant that no one ever mentioned HCV when I gave birth to my daughter and my blood was tested throughout my pregnancy. He was adamant that I did not contract the virus from the dialysis machine because they are thoroughly cleaned. Medical professionals have since told me that the blood I received was safe, so it was always implied that I contracted the virus from my own lifestyle choices.
26. During the 1980s and 90s the governments were continually saying that blood and blood transfusions were safe and so it made it even harder for me to try to explain to people how I contracted HCV. At times it even made me believe that I didn't get HCV through the blood I had been given.
27. In addition, I remember that women of a certain age group ie mine, who had got divorced became sexually promiscuous with their new found 'freedom' and were getting sexually transmitted diseases. Whilst I was not divorced, I was self conscious because of my age that others, particularly in a hospital environment where there was segregation for infectious people, may think I was in that category.

28. My lupus consultant, Dr Liz Lightstone undertook a comprehensive study to trace all of my blood donors in the 1980s. Of the donors found, there was no record of them having hepatitis, but she could not find the records of three donors. She was the only medical professional that looked into the blood I received and recognised it could be the source of my infection. I do not personally have any record of this research.

### **Section 3. Other Infections**

29. I have not contracted any infection other than HCV as a result of being given contaminated blood and blood products.

### **Section 4. Consent**

30. I never consented specifically to an HCV test and as far as I was concerned they were just checking my blood.
31. Nothing was mentioned about the virus until I was diagnosed.

### **Section 5. Impact**

32. I do not know if I had any symptoms from the HCV because they are very similar to lupus, but I was always tired, achy and experienced flu like symptoms. I now believe that the HCV symptoms were masked by my Lupus
33. I had extreme fatigue and could not get through a day without going to bed. On particularly bad days when I could not physically get out of bed, I would tell my daughter it was a 'jimmy jam day'. She would bring all her stuff to my bed and spend the day there with me.
34. I had a lot of aching in my bones and it felt like I constantly had weights attached to my arms and legs. I was told that I had a vitamin D deficiency, so was prescribed supplements.

35. The symptoms became a lot worse in the 1990s, but again, I put this down to lupus and then on my renal problems. It was very difficult to separate them. I found that my eyesight deteriorated and I suffered with blurred vision.
36. I experienced very bad brain fog at times and would be quite forgetful, but these are symptoms also linked to lupus. Sometimes I would get in the car to visit my father, but I would have to stop on the journey because I could not remember where he lived. I was told that the brain fog was due to my kidneys not filtering out toxins from my blood.
37. I suffered with bile nausea, which again was put down to toxins not being filtered properly by the kidneys. I would feel nauseous for a few days and my husband often commented how I turned a funny colour.
38. It is possible that lupus may have camouflaged the symptoms of HCV and this may be why I was not tested for the virus until 1997. After my diagnosis I was transferred to St Mary's Hospital, Paddington and I was seen by Dr Ashley Brown every six months.
39. Dr Ashley Brown carried out a liver biopsy. I had to lie flat for 12 hours after the procedure, but I was in so much pain and had deferred pain in my shoulder. I asked the nurse for paracetamol, but she sat me up in the bed, which she should not have done. I had a huge bleed, so was rushed down to surgery. I do not remember having any blood replaced.
40. The doctor had initially thought that he had nicked my liver during the biopsy, but the bleed occurred because the nurse had sat me up before I was allowed. The head nursing sister argued that it never happened, but there was no other explanation for the bleed. I was then referred to Dr Le Femme in the haematology department, to see why I bled so easily.
41. I have anti phospholipases (sticky blood), but I do tend to bleed out. He said that I was to have plasma before any procedure, to prevent excessive bleeding.
42. I was put back onto dialysis in 2009 as my kidneys had started to deteriorate again. In the 12 years since I last had dialysis, the hospital introduced segregation for

people with HCV and HIV. I was told that I would be in a separate room and could only use those machines.

43. Being segregated from non-HCV/HIV patients, reinforced my belief that I was infected by a dialysis machine. It also led me to the conclusion that dialysis machines could be contaminated between patients, otherwise why was I segregated along with other infected patients? I contracted HCV through no fault of my own, yet I was put with individuals who made poor lifestyle choices. Everyone on dialysis knew that I was infected because I could not be called up to use any of the other machines – it was awful.
44. I was given plasma before my kidney transplant in 2010. It was intended for me to have my husband's kidney, but my antibodies did not match and I had to wait on the donor list.
45. A couple of months after the transplant, the kidney was not working properly and I had to have a stent inserted. I was not given any plasma beforehand because the consultant was in a rush to travel down to Salcombe for the weekend. I was awake during the procedure. As soon as he put in the stent, I started to bleed out. He told the nurse to apply pressure, but I required a transfusion of 8 pints. I had to be resuscitated and ended up on a high dependency ward. They had to bike over a vascular surgeon from Kings Cross. This was the only incident I ever complained about – the NHS upheld the complaint and paid out £20,000 to me and £45,000 to my solicitor for the legal fees.
46. Whilst living with HCV, I found a little ulcer on my vulva would not heal – I had no idea what it was. It was very sore and open and this added to my anxiety about having sex. I was referred to the Queen Charlotte Hospital in London, where I was diagnosed with cancer. I had to put an ointment on the sore every night that burnt the cancerous cells – the cream caused excruciating pain, but it healed the cancer.
47. All medical problems are blamed on my immune system not being very good. Last year I had septicaemia and this was also put down to my poor immune system.
48. In 1997/98 Dr Ashley Brown said I could not have the treatment for HCV because it would destroy any future kidney transplant. He said that the treatment was awful

and there was no guarantee that it would work. It was also mentioned that the NHS would only fund one round of treatment, as it cost £30,000.

49. His advice was to wait until a better treatment was available and that my renal treatment should take priority for the time being.
50. A scan was taken of my liver and they said its condition was at level 3. I got the impression that this was good.
51. After my kidney transplant I was told that I could not have the treatment at all, because the medication was not suitable for transplant patients. It was interferon.
52. In 2018 I was offered a new treatment in tablet form only, that was safe for my kidney. The length of treatment was 12 weeks. The tablet had to be taken at a certain time and after food. I was told that I could not even miss one tablet during the course because it would ruin the treatment completely. I was also reminded that the treatment cost £30,000.
53. I originally took the tablet in the morning, but I started to experience terrible itching. I told the HCV nurse at St Mary's and she advised that I took the medication in the evening instead, so that I could take a sleeping tablet and an antihistamine. She commented that no one had ever complained about itching before.
54. I was told that the medication had no side effects, but I suffered with itching and nausea and I still experienced fatigue. During the treatment, I attended St Mary's for testing and monitoring frequently – more so at the start as it tailed off towards the end.
55. I had to wait a further 3 months after finishing the treatment, before the doctors confirmed that my viral load was not detectable.
56. I have never been told that I am cured of HCV because there is no guarantee that it will not come back, but it is now undetectable. I am continually monitored by the renal clinic.
57. The treatment made a huge difference to my health. I started to have a lot more energy and felt less sluggish. I lost a stone and a half after joining weight watchers



and I started to go on holiday with my friends. It became clear that the symptoms I put down to other health conditions were predominately due to the HCV.

58. I felt so much better after the treatment (at the age of 60) than I did in my early 40s. I had a lot more life in me compared to the years leading up to the treatment. Once my viral load was undetectable, I felt that a weight had been lifted. I did not have to tell my nail girl to put gloves on anymore as I could no longer pass on the virus.
59. If I ever had a medical procedure, I would say that I was HCV positive – in case they did not know. I often had to go to Ashford Hospital in Surrey for blood tests and there was only a curtain in between the waiting room and where your blood is taken. I would say about the HCV very quietly, to prevent the people in the waiting room from overhearing, but the nurses would speak about it loudly. I found this very embarrassing as the other patients could hear everything going on and they would know about my infection. I felt very stigmatised.
60. On one occasion I wrote down my HCV status on a piece of paper, but the nurse was foreign and did not understand and so again I had to say it out loud.
61. Whilst on holiday in Bournemouth, I became unwell and was taken to hospital. I told them about the HCV and they took me into a side room where the doctor asked lots of questions about the virus.
62. I was always made to feel that the infection was my own fault and my husband used to get frustrated by this. I constantly had to explain that the virus does not necessarily come from drug use or was sexually transmitted.
63. All medical professionals kept quiet about contaminated blood and I was always doubted as to where my infection came from. Even Dr Ashley Brown would say it was doubtful that I contracted HCV from the dialysis and never mentioned the blood products I received in the 1980s and 90s.
64. I am frightened to go back on dialysis if my kidneys fail again, because I will be segregated with the HCV and HIV patients. I should have been treated as a special case from the start, rather than being lumped with individuals who contracted the virus due to their lifestyle.

65. I told my dentist, Katie at the Green Street Dental Practice in Sunbury about my HCV infection. She would cover herself up in PPE and before any dental work, would insist that I take a course of antibiotics to prevent infection. I did not want to keep going this, so I was referred to a practice at Knowle Green in Staines for people that had trouble going to the dentist. I continued dental treatment at Knowle Green after my HCV infection was undetectable, but because of cut backs I had to go to another dental practice. I chose one in Staines. I no longer had an infection to declare.
66. I think I told quite a lot of people about my infection because I was so shocked. I told my friends who I go on holiday with, so that they were aware of the risks if I cut myself.
67. I never told my parents about HCV as GRO-C and it would have opened a can of worms. They would have been disgusted and probably would not have believed me about the cause of infection.
68. The ignorance around HCV has always made people assume that it is a dirty, sexually transmitted disease, so I would always have to explain that I did not contract the virus from my lifestyle choices.
69. I remember one occasion I went to church and my friend remarked to the priest how I looked good "considering she is on dialysis". He replied "oh! you are the one costing the country and lot of money" and walked off. I never went to church again.
70. I do not like sharing food and did not feel comfortable at buffets because of my HCV infection – I would not join in because I did not want to touch the food.
71. I still insist that my husband does not drink out of my glass because it has become a habit.
72. If anyone asked to have some of my water, I would say there was aspirin in it as I would worry about infecting them with the virus.
73. My work life was destroyed by my medical conditions. The lupus did not affect me as much as the HCV, as the steroids enabled me to carry on working.

74. In the 1980s extreme fatigue made it hard for me to go into work. In hindsight, this was probably because of the HCV infection, because the lupus was under control with the steroids (albeit a few flares). I stopped working at Clinique in the 1980s because I could not cope with travelling around the South West to train employees. I then had started a job with Revlon, but I became very unreliable due to my health.
75. I will never know whether my working life was cut short due to a particular aspect of my health conditions, but fatigue was definitely the biggest inhibitor of me being able to work and I am aware this is a common side effect of HCV.
76. I did make inquiries about holiday insurance and notified the provider of my health conditions (including HCV), but the premiums were hundreds more and made the holiday cost prohibitive. They were significantly lower if I did not mention the HCV.
77. My doctor assured me that I would not become very sick from the HCV or my renal problems in a short period of time, which made it possible to travel, without declaring my HCV for the insurance cover.
78. I did not go back to places like the Caribbean after my kidney failure and HCV diagnosis, as I felt that I would not receive sufficient medical attention in less developed countries.
79. My husband was concerned about transmission of the virus and was very strict if I had any cuts. On one occasion I cut myself with a knife and there was a lot of blood because I was taking aspirin. David shouted at my daughter to keep away from my blood, so I then had to explain to her that I had an infection.
80. My HCV diagnosis had a very big impact on my intimate relationship with my husband. I was scared that I could infect him if I had a cut anywhere and I could never relax.
81. GRO-C I recall him saying in front of friends that I had HCV and I could have potentially given it to him. I do not think we had any sexual relations until GRO-C. GRO-C improved things for him afterwards, but it did not improve for me. I did not enjoy it anymore – I wanted it to be over and done with and for my husband to be safe.

82. After Liz Lightstone confirmed that HCV is rarely transferred between sexual partners, our intimate relationship went back to normal. I felt comfortable opening up to her about this subject, because she was a female medical professional.

83.

GRO-C

84. My daughter was only 10 years old when I was diagnosed with HCV, but she was very resilient.

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

85. In 2009 (just before my kidney transplant) I was offered counselling at Hammersmith Hospital. I would have had to travel some distance for the sessions, so I declined the offer. This counselling had nothing to do with my HCV.

86. I had a 12-week course of Cognitive Behavioural Therapy (CBT) in 2000 to help living with a chronic illness. It was organised by my GP, as a result of all of my medical conditions (including HCV). I had one session per week.

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

87. I applied to the Skipton fund for financial assistance in 2006, but they wrote back a few months later to say that the clinician had not filled out the application form properly.

88. From what I recall, I had to prove where and when I contracted HCV. At this point, I thought I was infected just before 1997 (when I was diagnosed), to which I was told everything was safe at this point and therefore I could not receive financial support.

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

89. I do not care about the money, but I would like recognition that I was given HCV through no fault of my own. It has always been implied by medical professionals that I contracted the virus because of my lifestyle.
90. We can all make mistakes, but the use of contaminated blood and blood products should not have been allowed to continue for so many years.
91. I would like there to be a regulation to prevent this from happening again.
92. I now question everything medical because I have suffered by not doing this before.
93. For reference purposes here is a comprehensive list of my medical conditions:
- Systemic Lupus Erythematosus (SLE)
  - Nephritis – a renal infection
  - Antiphospholipid syndrome (APS)
  - Cancer of the vulva
  - Heart disease - caused from the high dose of steroids prescribed to treat SLE
  - I have 50% reduction of vision in my left eye – I had massive bleeding behind my eye and the veins had to be sealed with a laser.

#### **Statement of Truth**

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

Sign GRO-C

Dated 2-10-2020.