Witness Name: Mrs Delia Wetherall
Statement No.: WITN1998001
Exhibits: WITN1998002-WITN1998008
Dated: 19 December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MRS DELIA WETHERALL

Section 1: Introduction

1. My name is Delia Wetherall. My date of birth is GRO-C 1960. My address details are known to the Inquiry.

2. I am married to my husband of 40 years, Bill, and have three adult children, Nicola, Lee and Aimee. My fourth child died in 1985 at two months old from Sudden Infant Death Syndrome.

3. I am originally from London, but over the last few years we have been residing in the countryside in Spain. My employment for approximately 25 years was working for the London Borough of Hounslow Social Services supporting children and families in crisis, a job I enjoyed immensely. I worked there until my health seriously deteriorated to the point I could no longer manage to work, and I retired on ill health grounds.

Section 2: How Infected

4. I received blood transfusions before and after giving birth at Margate Hospital in Kent in 1979 and West Middlesex Hospital in 1981, 1985 and 1986. I believe these transfusions were given due to anaemia but not in an emergency situation, just to help me recover faster. To date I am still anaemic.

5. I was told on each occasion that I would be receiving a blood transfusion but I was not told of any risks involved.

6. I believe I was infected with HCV only.

7. Throughout the early years when my children were growing up, on numerous occasions I made appointments to see my GP who regularly sent me for investigations to determine why I was feeling exhausted and couldn't figure out why. I had lost a lot of weight and was feeling generally unwell. The GP told me that was likely because I was running around with the children, and suggested that I take iron tablets.

8. Around 1991 my family moved house, and I took my oldest daughter to register with a new GP because she was feeling unwell. While we were there, the GP told me that I should make an appointment for myself because I looked like I had lost weight and didn't look too good. I was surprised by this as I had never met this GP before. I made an appointment with her, and at the appointment she said she was going to send me to Ashford Hospital to have numerous blood tests. I wasn't told what the tests were for.

9. I went to have the blood tests at Ashford Hospital, but was still not told what the tests were for. About a week later, I received a phone call from the hospital saying to come in and receive my test results. I went in and the doctor told me that I had HCV.

10. I have seen in my hospital records that I was tested at the time for both Hepatitis B and C, and it was noted that this was because I had had blood

transfusions. **(WITN1998002)**.

11. I didn't know what HCV was at the time, but I nearly fell of the chair with shock and told the doctor he had the wrong results in front of him. I have never put myself at risk for anything, so I was flabbergasted by it all. The doctor told me that I needed to be counselled about my HCV, and sent me to a room to speak to a nurse.

12. The nurse that I saw did not provide me with any information about the prognosis of HCV or how to cope with it. Instead, she asked me if I was promiscuous, if I took drugs, and if I was an alcoholic. I was offended by this because the doctor knew that my infection was due to blood transfusions but I was still being made to listen to a lecture from a nurse that was clearly intended for people who had contracted it through lifestyle choices. I thought, I have done none of these things! Then I think the nurse said something about me being lucky that I didn't have HIV. I walked around for days in a daze not knowing what to do or what to say.

13. I went back to my GP after that, because I was still very tired and wanted to see if there was anything I could do about it. My GP decided to lay out my notes on her desk and look through them to see if there were any clues as to what might be causing my tiredness. She mentioned that previous blood tests had shown that my liver function was raised, and said that there was a note in "Other comments" on the document showing the results of my blood tests, saying "please check". However, there was nothing after that to indicate that it had been checked. I did not see this document myself and have not been able to find it in my records since, but took my GP's word for it at the time. My GP then said she would send me to hospital to have further checks on my liver.

14. I was referred to Kings College Hospital in London in 1992, and have stayed under their care for my liver testing since then. I remember when I went there for the first time, the liver clinic was in the location of the old fracture clinic. When I walked in, I was surrounded by people who were yellow, very skinny

and weak. One of them asked me to help them take the top off of their bottle of medication, because they were so weak they couldn't open it themselves. It was very scary as I thought this is going to be me in the future.

15. When I saw the doctor, they confirmed I did have HCV and said they would do blood tests every few months to check my liver function. They did not give me any information about how to look after myself or about the virus in general.

16. I do not feel I was given adequate information by Ashford Hospital as the hospital said they didn't know much about HCV or how to manage my infection. My care was meant to be "shared care" with Ashford and Kings but I stopped attending Ashford Hospital and all my care remained at Kings College Hospital.

17. I think that I should have been tested earlier for HCV. I had gone to see my previous GP before we moved to GRO-C in Middlesex, but no one had thought to test me for HCV based on my symptoms, even though I had raised liver function results.

18. I do not feel the way that my diagnosis was communicated to me at Ashford Hospital was appropriate. The doctor told me of my result and promptly sent me to speak to the nurse, who treated me as if I was an unsavoury member of the community. I feel there could have been better communication between the doctor and nurse so that I was given relevant information about the virus, how I had contracted it and what I should do next. I remember thinking at the time, "what the hell is happening" and feeling very scared.

19. The only information I was given about how to live with the virus and avoid infecting others was that I was told to tell my husband to wear a condom. I was not told of any other routes of transmission, or of how I could adjust my diet to help my liver.

20. After my diagnosis, I went to the hospital every few months for monitoring. They moved the liver clinic from the old fracture clinic to the lab for blood tests. My doctor at the time really did not seem very concerned about the long term

effects of HCV. I remember asking what the prognosis would be, and him saying that if I smoked, I was likely to die of that first. The implication was that I wouldn't see any damage from the HCV for many years, so I should not worry about it.

21. Later, they started a special clinic just for people with HCV. I went there several times to have blood tests done, and I was never updated on the results of these tests. I was concerned that I wasn't being told about any treatment options.

Section 3: Other infections

22. I believe I have been infected with HCV only.

Section 4: Consent

23. I do not believe I was treated without my consent. Back then, it was a different thing. You trusted doctors and nurses to do the right thing. I was brought up that way and didn't question about the treatment I was given and believed it was always in my best interests.

Section 5: Impact

24. The main physical effect of HCV for me was the extreme tiredness. I also had headaches and began sweating. The tiredness was not a normal tiredness, but a severe exhaustion where I couldn't keep my eyes open, which was extremely challenging as I was looking after three children.

25. I have experienced mental health issues, this mainly being depression on a few occasions mostly from the effects of the treatment I have taken for HCV. To date I still take anti depressants as a result of this.

26. After my care was transferred to Kings College Hospital, shortly after my

diagnosis, I began to attend regular monitoring appointments there where blood tests were done. After a few appointments, I became concerned that the clinic doctors weren't offering me any treatment for my HCV and was instead using "wait and see what happens" monitoring. I felt too unwell for this and wanted to know if I could access any treatment.

27. I asked one day if I was going to be treated for the HCV, and I was told to come back to the clinic on a different day, where my treatment options were discussed. It was determined that I should take interferon treatment. I was prescribed the medication, given a demonstration on how to inject myself, and allowed the opportunity to practice giving an injection into an orange, I was admitted into Kings College Hospital for a few days until I was competent to administer injections to myself **(WITN1998003)**.

28. I took interferon treatment for about two years from 1992-1994. The treatment was horrendous. They had told me that I would get flu symptoms, but these were not flu symptoms. I had never experienced symptoms like this before. I was so exhausted, I just stayed in bed. The depression was terrible. It was like everything seemed dark and dismal and the happy cells had been taken out of my brain. My bones ached. I kept having to go to hospital because my haemoglobin levels kept dropping, requiring more transfusions. It was awful. I wouldn't wish that treatment on my worst enemy.

29. The only reason I came off of that treatment was because I nearly collapsed at work. To be honest, I don't know how I carried on with it for two years, but I just thought, I had to get through it. On that occasion the treatment wasn't successful and the HCV remained.

30. A few years later I tried another course of interferon treatment. This treatment failed as well. Both courses of interferon treatment caused serious complications, including what was deemed "Interferon-related bone marrow hypoplasia" **(WITN1998004).** In fact, I was initially deemed not a candidate for pegylated interferon and ribavirin because of bone marrow hyperplasia **(WITN1998005).**

31. I continued to be monitored during this time at hospital, and it was determined that I had cirrhosis of the liver.

32. In 2010, I took a course of treatment of pegylated interferon, ribavirin and adjunctive filgrastim. This treatment lasted 27 weeks. It was meant to last 52 weeks but I had to stop it early as I became too anaemic. **(WITN1998006).**

33. The side effects during this third course of treatment were similar to the ones I had with the interferon. This time, I was given anti-depressants in advance of starting treatment, to prevent me from getting as depressed as I had last time. However, this didn't work and I still felt depressed. To combat the side effects I had to have a lot of other medications, such as injections to maintain my blood cells. In spite of this, my weight dropped to nearly six stone, I couldn't breathe, and I had to stop the treatment because my haemoglobin was so low.

34. My doctors always told me to wait and let my body heal itself from each treatment before trying another one. However, even today I don't feel as if I have healed. I have just continued to gather side effects from each treatment, some of which have never gone away.

35. In 2015 I went on a 12 week course of Harvoni with ribavirin, which resulted in me clearing the virus **(WITN1998007).**

36. During this treatment I experienced more side effects. My teeth started to rot, ooze and fall out to the point that I had to get dentures.

37. I have continued to experienced serious health issues and complications for many years now which I believe are the result of the HCV, and the medications/treatments. I was a healthy person before I received contaminated blood via transfusions.

38. I developed double pneumonia in 2015, and had to have two main heart valves replaced for which I take coagulation medication every day for the rest of my life. My blood is monitored on a regular basis for this. I see the heart specialist

in Spain once a year now and if I have any problems outside of that time I can also go to see him.

39. In 2017, I had ocular tuberculosis, encephalitis, parvo virus, and pancytopenia. I was rushed to the hospital in Spain because all my faculties went; I couldn't speak, see or walk, was confused, had diarrhoea, was sick; it was very frightening. I stayed in hospital for two months at that point. Psychiatrists came to see me at my bedside to speak with me because I didn't know what I was doing, I couldn't speak properly. I have never been on so much medication at once; orally, IV – it was relentless, for 5 weeks. This is why we ended up settling in Spain as I had to keep going to the hospital for appointments and monitoring which is still the case today.

40. I had many scans after this – CT, bone marrow, biopsies, lumbar puncture – and stemming from this, I am still on a lot of medication. At this moment, I am being seen by the heart specialist, dermatologist, eye specialist, auto immune consultant, haematologist, and psychologist in Spain, and the liver specialist at Kings College and associated dentist, every six months in London to assess the state of my cirrhosis and conduct surveillance of any developing liver cancer.

41. I had some difficulty finding a dentist who would treat me initially. I tried to sign on with a dentist and he would not take me on because he said there were too many people registered. They didn't say in so many words that they didn't want to treat me because of my infection, but that was the implication. When I desperately needed dental treatment due to the side effects of the interferon and ribavirin treatment, I asked my consultant at Kings College to refer me to the Institute of Dentists. I received my dentures there and still go there today.

42. I also experienced some delays in obtaining HCV treatment. Shortly after my third treatment I was told by my doctors at Kings College that I would be able to have Harvoni treatment, but then it turned out I wasn't able to get it until three years later because NICE had not approved it yet. Once it was approved, it was given to 500 patients a time. The first 500 patients were people who were

projected to have 6 months left to live due to liver cancer, and I believe I received treatment in the second group of 500 patients.

43. The medical team and staff at Kings College Hospital have always been very good to me. There has only been one occasion when I became angry at Kings. This was when the Skipton Fund was coming into effect and one of the consultants treating me made a comment about how I would receive free money from the government. I raised my voice at him, and another consultant came in and asked him to leave the room. I never saw him again.

44. The HCV and treatments have had a significant effect on my family life. When my children were young, I couldn't really go out and do activities with them, like going roller skating, because I was always tired. I tried to go to their parents' evenings and most times I did manage it, but eventually it all became too much. I have always been upfront with my kids, and they have always helped me when needed. My oldest one used to help me out of bed when it was time to do my interferon injections. My illness has had a huge impact on them, as they constantly had to hear "Oh we can't go out today, Mum's not well again, Mum's at the hospital." As a family we missed quite a lot.

45. My grandson asks "Where's Grandma?" and the answer is always that I am at the hospital or the doctors. I don't want to be known as a grandma like that, but that's the truth. Why would my daughter lie and say I was elsewhere? As a result all the children have known is that I'm not well. They have had a life of me being ill and me having to fight the benefits agencies for assistance. It seems like the focus is always on me, when really I would like it to be on my children and grandchildren.

46. I used to be very outgoing, bubbly and a positive person but being given HCV and the after effects has taken that away most of the time, although sometimes I see glimpses of my outgoing bubbly self. This virus has seeped into every area of my life and my husband's life. For years and years I have suffered from seriously ill health, a lifetime of hospital appointments/treatments and

medications which has become a *normal* part of everyday life. This should not be so.

47. My husband and I have been together for 40 years, and I am so glad for his support. He takes me to every hospital appointment, even though I don't want to go, I just want to have a normal lifestyle. My husband takes care of me everyday with no complaints. He drove 50km each way to the hospital in Spain every single day for two months when I was there as an inpatient, and stayed from 11am to 7pm. If he wasn't around I probably wouldn't be able to take care of myself as much. He has been a rock. I have had some difficult times where I have lost the plot and been really nasty, where the anger is aimed at my husband. I even tried everything in my power to get rid of him last year as I thought he wasn't enjoying life and I didn't want to be a burden on him. I thought that if he was rid of me, he would have a life of doing what he wants to do. I just didn't want him to stay with me and have to care for me. It's a life of hospitals and doctors and medication. But we do have our good times as well, we always have a laugh.

48. I have never experienced a stigma against HCV - certainly not compared to what others have gone through. I'm very upfront, a lot of people know I was infected, but I don't really mind what people think about it. I know of a lot of people who have experienced stigma and have been treated in a disgusting manner.

49. I started my job in social services in 1990. Around 1994, the occupational health service asked me to retire because of my HCV. I believe my doctor at Kings sent a letter and information to the Occupational Health service saying that I was not a risk to clients, and that DHSS would not award disability benefits to someone because of having HCV because they assess us as capable of working. The letter enclosed a copy of a report called "*Hepatitis C virus: guidance on the risks and current management of occupational exposure*" from September 1993, which stated that there had been no reports thus far of transmission of HCV from an infected health care worker to a patient

(WITN1998008).

50. My work required long, hard shifts, going into the community and supporting families in crisis. I really loved it. The reason I went into that work was because as a child, I was in a Children's Home in GRO-C Bristol with my brother and two sisters. We were told it was a two week holiday that turned into 10 years When I came out of care, my dream job was to help others in that situation.

51. I went on sick leave from work for about two years in 2004. My work was very understanding, and let me take time off, but I did have to go to the occupational health service a lot to discuss this with them. By the time I was 50, having worked in social services for over 20 years, I was starting to really feel ill and struggling to do my job. I couldn't think straight, my bones were aching, I had so-called flu symptoms. The hospital told me that I should think about taking redundancy if I was struggling to work due to my illness. I ended up retiring early in 2010 on health grounds.

My husband no longer works for British Airways and left his job after 15 years in order to look after me.

52. I had never signed on to benefits up until that point, as I had always worked. I tried part time work; I had a six month contract supporting young people to find work or further education. After that, I knew my working life was coming to an end as I felt so ill and drained. I went on benefits. I had to have an assessment for DLA in London. The interviewer was very rude; when I sat down he immediately told me to take my coat off the table. He then asked me questions about my mobility, for example, if I could move my arm in the air, and walk up and down a few steps. At first I thought it was a joke as at the time this was nothing to do with my illness, the effects of medication or day to day management of looking after myself. A week later I got a letter saying I wasn't eligible for Employment Support Allowance because I was deemed fit for work.

53. To be honest I was so angry not being eligible for benefit support that I decided to complain about the decision made. I put my complaint in writing but was told

by the Job-centre my complaint was unlikely to be upheld as only a very small percentage get their decision upheld. I explained to them that I have worked full time for many years. I worked hard, I paid into the system, and now am unable to work due to the effects of my illness, given to me from contaminated blood and none of this was my fault. A couple of months later I received a letter stating the decision was upheld and I was entitled to benefits and unable to work. All monies owed were paid back to me.

54. For a few years I was entitled to DLA and was given a mobility car, but since living in Spain on a more permanent basis, I have not re applied for this benefit as I'm not sure I would be entitled.

55. I have to say that the medical care I have received in Spain has been excellent. The hospital in Granada asked me if I needed financial help to attend appointments, and offered me rides home in the ambulance, even though my house is 50 km away. My GP there told me that I could have a welfare officer to help me fill in necessary forms and keep track of my appointments, so I stay in the system and don't forget about anything. I have also have an interpreter to help me communicate better about health issues, for example like dietary needs and daily exercises. When I was being treated as an inpatient, a relative of a heart patient who was a hairdresser came and washed and styled my hair also pushed me downstairs in a wheelchair to go in the shop. When I was in hospital at Christmas 2017 and couldn't see very well, the nurses put up a star light Christmas decoration on my door so that I could find my way back to my room unassisted.

56. My experience of the Spanish health system has been extremely good with clinical excellence. It's completely different to the NHS. It's not overcrowded, they don't try to push people to go home early to make space for more patients. You don't have to wait months for treatment, you can always get an appointment in a few weeks.

Section 6: Treatment/Care/Support

57. I have never faced difficulties obtaining treatment aside from the delay in receiving Harvoni treatment that I mentioned above, and the difficulties I had finding a dentist.

58. No counselling or psychological support has been offered to me. The only "counselling" I received was when I was first diagnosed and sent to a room with a nurse who asked me about my sexual and drug history.

59. I have separately had some counselling for depression in Spain.

Section 7: Financial Assistance

60. I found out about the Skipton and Caxton foundation by searching on the internet for HCV in about 2004. I wanted to see if there was any financial help available as we were struggling.

61. I phoned up the Skipton Fund for an application form, the consultant at Kings filled in the form, and I received the Stage One payment right away.

62. I then applied to the Caxton fund for assistance. I used to have a caravan near the beach in England and I used to go there on a regular basis when I was on treatment, so I asked them if they could they renew the lease for the following year because I would still undergoing treatment. They said no, and I never applied to the organisation again.

63. I now receive monthly Stage Two payments from the Skipton Fund.

64. This has been okay for me until recently, when I needed assistance with a few extra expenses. Since contracting ocular tuberculosis, my eyesight has been compromised and I needed new glasses, I applied to the Skipton fund and was told after filling in the application form that there was a requirement to submit a request within three months of paying for the glasses to be reimbursed. I had submitted the application after the three month deadline passed and was

informed I was out of time and could not be reimbursed the £300 I paid for the glasses. I explained that I had ocular tuberculosis as well as other serious health issues and that I had been partially sighted but was informed this did not make a difference as I was out of the time-frame.

65. I also applied for reimbursement of petrol expenses for my travel to the hospital in Spain. The Skipton Fund said they were not sure about my entitlement to this as they were not sure if they could pay for travel outside of the UK. I have received payment for some appointments, but the rules seem to be inconsistent. I now have to fill in a new form every three months for the travel, and take photocopies of all hospital appointments with evidence of how far the hospital is from home. They cover my travel expenses to Kings College when in the UK, but sometimes say that they don't cover travel to the dentist there. After refusing my glasses application because of the three month time limit, they have subsequently reimbursed me for travel expenses for some appointments more than three months after I attended them.

66. Unfortunately I haven't found the support schemes very helpful. I feel they are not fit for purpose. It appears the organisations put so many obstacles in the way to prevent people getting financial support. There are many hoops to jump through which is very difficult especially when we are ill. I believe the whole support system needs to be looked at again with the view of making applications simpler.

67. Although I haven't been asked to supply quotes to the support schemes, my opinion is this is very degrading and embarrassing, especially in this day and age. There is a stigma attached to doing this. Many years ago when I worked in a children's home, the system was to get quotes and amounts to buy the children clothes, however this has not existed for several years now.

Section 8: Other Issues

68. In terms of what I expect from the Inquiry, I just want to know the truth. Why

would somebody do this to people? Why would someone be so cruel as to save money/resources by infecting thousands of people? This was very short sighted as the government will not save money due to seriously ill people needing continuous health care and support. At some point compensation will have to be paid to many people.

69. When I came out of care all I wanted was a family to look after, but it never quite worked out that way. Somebody has taken the lives that we could and should have had away, and we need to know why and the truth. I want the government to put their hands up and say "Yes, we did that" instead of putting things off and dangling a carrot to us in the form limited financial assistance, before taking it away again. I believe there should be a compensation package in place for the infected/affected to meet the needs of the people, and no more begging bowls or dangling carrots. In addition to full compensation and instant access to government benefits if needed, I think there should be health cards distributed for patients to access the best of services and support available, and life, holiday, health and any other insurances being paid by the government.

70. HCV creeps into everything that you do. Even when I was deciding where to live in Spain – we had bought a house, but because of my health issues it was too cold for me and because of its construction it was impossible to put in central heating, so we had to rent somewhere else instead. I have to constantly take medication and feel the cold badly. Cleaning my teeth takes half an hour. And the way they have treated us over the years is so terrible. If you told people about this nightmare in conversation, they would probably think you were making it up. People just look at me like I'm crazy, because I don't necessarily look like there's something wrong with me when you see me.

71. I'm so glad for this Inquiry; it made my year when the Inquiry was announced. Sir Brian is my hero. I think he and the Inquiry team have got a very good understanding of what has been going on. But I also think that unless you're in it, you don't fully understand the impact. Thank you – Thank you – Thank you for all your hard work.

72. Years ago, I used to write letters to the government. In my everyday life I inform people of the infected blood scandal and the impact on people it has caused. The doctors in Spain know about it and they want information from me about it when I see them. When I was on Harvoni the doctors wanted the leaflets from it and I talked about it quite openly with them. Although I'm not in the front lines, I do my own education about HCV and the impact, because I think the whole world should know about the contaminated blood scandal, and the misery and heartache it has caused.

Statement of Truth

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

Signed GRO-C

Date .. 19 December 2019........