Witness Name: Marie Petranella Aiyadorai
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARIE PETRANELLA AIYADORAI

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 September 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Marie Petranella Aiyadorai, will say as follows:

Introduction

1. My name is Marie Petranella Aiyadorai. My date of birth and address are know to the Inquiry.

1.1. I am a retired nurse. I trained at Frenchay Hospital in Bristol where I started to work in 1967. In 1969 I also did my midwifery course at Sorrento Hospital in Birmingham but I never practice.

1.2. I am married and I have a daughter and a son.

1.3. I intend to speak about my life and how I came to be infected with the Hepatitis C Virus (HCV).

1.4. In particular, I will go into details on how the contamination has impacted on my general health and wellbeing and how the illness has affected my relationship with my husband and my kids.

1.5. I have been asked if I am currently represented, the answer is no.

1.6. I am content for my statement to be taken by the investigators from the Inquiry. My husband, Basil Aiyadorai also assists me, as sometimes my memory is not very good especially with dates and names.

How Infected

2. I was infected with the Hepatitis C virus (HCV) through a blood transfusion. I am not sure as when it actually happened because I had several blood transfusions in my life.

2.1. In 1974 at Cardiff Royal Infirmary I received 2 units of blood and between 1979 and 1986 at West Middlesex University Hospital I received probably 6 more units, all of them as a result of severe bleedings.

2.2. Later, between 1986 and 1988 at West Middlesex University Hospital I had some further blood transfusions as a result of one of the surgeries I underwent (I do not recollect the exact dates). At first, during a cholecystectomy, I received 2 units of blood and then, during a hysterectomy I received approximately some other 4 units. I am not sure which one of the units I received, contained the infected blood.

Background

2.3. I have been a nurse since 1967; I have worked at West Middlesex University Hospital since 1975 and at the Social Services in Hounslow since 1989-1990.

2.4. On the 2nd April 1975 I married my husband Basil Aiyadorai.

2.5. I have always suffered of severe bleeds during my periods, which resulted in several transfusions. I remember that in 1974 the doctors in Cardiff gave me 2 units of blood and even later on, after I got married, in between 1979 and 1986 I received a further 4 units at West Middlesex University Hospital. My haemoglobin has consistently been very low.

2.6. In GRO-C 1979 I naturally gave birth to my daughter at West Middlesex University Hospital. I had a traumatic delivery and because her shoulders were stuck, they had to use forceps. GRO-C GRO-C

2.7. After her birth, I started again to bleed heavily during my periods. A specialist at West Middlesex University Hospital said that my haemoglobin was very low and he advised me to undergo a hysterectomy. He also explained me that if I wanted to have a second child, that (obviously) had to happen before the surgery.

2.8. After my daughter's birth, I definitely wanted to have a second child but I didn't want to go through the same horrible experience. In GRO-C

1983 I gave birth to my son via a planned Caesarean section and everything went as scheduled.

2.9. As planned with the doctors, between 1985 and 1986 (I don't remember the precise period, I remember it was autumn) I then had a hysterectomy. During the surgery I received approximately 4-5 units of blood and then I stayed in the hospital for about 2 weeks. When I went back home everything was fine and life went back to normality.

2.10. Between 1986 and 1988 (again, I don't remember the exact date but it was definitely before we moved house in 1988) I had a full cholecystectomy operation. During that surgery I received another transfusion of two units of blood: one unit before the surgery and one after.

2.11. Recently, my husband and I have been told by a friend of ours (she is a nurse too) that one of her colleagues who were assisting in the theatre during the cholecystectomy said that the doctors almost lost me during that surgery. Our friend doesn't know what happened and she doesn't now any other detail but she was told that there were serious complications.

2.12. This is what I have been referred but at that time nobody told me anything. Actually I remember that I felt fine after the surgery. I stayed in the hospital for about 6 or 7 days, but that was a normal procedure and the doctors were happy of how I recovered.

2.13. I think I contracted Hepatitis C from the blood that I received during these surgeries. I am not sure from which transfusion and because at that time we didn't know anything about Hepatitis C, the doctors didn't look up for it. But I think that I must have caught it from there. The blood transfusion had nothing to do with the first birth or with the C-section.

2.14. After the kids were born I went back to work part-time (during the week and weekends), as my husband was working during the week and we had to take care of the children. In between the cholecystectomy and hysterectomy I restarted to work as a nurse at West Middlesex University Hospital but after the second surgery, around 1989-1990 I left the hospital and joined the department of social services in Hounslow.

2.15. I loved my job and I wanted to progress in my career, but I couldn't, my physical condition was not allowing me to do so. So I joined the social services in Hounslow as a Resident Social Worker. I was in charge of supervising and helping out with the patients and the issues that the different places had. People who needed to go to hospital, patients who needed certain medications, residents with learning difficulties and similar tasks.

2.16. In 1993-1994 my liver started to have problems. I had all the symptoms that we now recognise as symptoms of the Hepatitis C but my doctors didn't know about them at that time.

2.17. I was unwell, I felt nauseated, I lost my appetite in a way that as a nurse I knew it wasn't normal. I couldn't face any food, I was losing weight and the smell of food bothered me. I was coughing and this caused me the very unpleasant effect to have a bad breath. I couldn't sleep properly; I was twisting and turning during the night. I was always tired, I had mood swings and I used to get angry and moody with no particular reasons. I had dizzy spells and very frequent headaches.

2.18. So my GP referred me to a specialist at West Middlesex University Hospital who run some tests and who in turn referred me to another consultant at Chelsea & Westminster Hospital. This time they did a further checks and a biopsy.

2.19. In autumn/winter 1993 the consultant at Chelsea & Westminster Hospital rang me and told me over phone that I had a form of Hepatitis. He said it was a new infection just discovered and that it was neither Hepatitis A nor Hepatitis B (later on it was defined as Hepatitis C). Nobody knew anything about it at that time. Even my GP actually told me that she just recently read something about it.

2.20. The consultant at Chelsea & Westminster Hospital also confirmed me that my liver was in a very bad condition and he said that I needed a transplant. I was shocked because during my nursing I heard about kidneys and other organs transplant but never a liver one.

2.21. Following this diagnosis I was then referred to another consultant at King's College Hospital, who was a liver expert. They immediately put my name on the liver transplant waiting list.

2.22. After 6 weeks only, they found a new liver and they called me. It was an early morning of a day in July 1995, I clearly remember it was 7.00 am as the day before I had been out the whole day with my family because my daughter had just taken her O levels and she was home.

2.23. They phoned me saying that they would have sent me an ambulance with police escort to go to the hospital. But I said that I wanted to go with my husband and daughter, not with a police escort. So I went there with my family and I had the liver transplant. I have been told that I was the 7th patient in Europe to receive one.

2.24. Apparently I was in theatre for more 16.5 hours. The surgeon who did the transplant said that despite some difficulties, the surgery went well. I don't know whether they made any transfusion during the operation.

He said that the new liver would have now given me a higher expectation of at least 3-4 years of life but he didn't add any other detail.

2.25. I stayed in the hospital for 4-6 weeks. Initially my body started to reject the new organ but the doctors took care of it and they allowed me to go home. I felt a bit of discomfort at time but overall I felt fine. After the surgery I had to go to the hospital every three months to do the liver function test: they monitored me quite closely.

2.26. At the beginning of 1996 I was forced to go into medical retirement and I struggled so much to cope with it that the doctors had to prescribe me antidepressants (and I am still taking them).

2.27. At the end of 2005, the doctors at King's College Hospital said that the Hepatitis C virus was still in my body and that the new liver was getting damaged because of it. After this diagnosis they decided to put me on two new medicines: Interferon and Ribavirin. At first, before the transplant they gave me Interferon only, but because it was not working, after the liver transplant they added Ribavirin.

2.28. As I explain below, those medications put me through hell and despite their side effects, the treatment didn't work and the the virus was still in my blood.

2.29. In 2016/2017 the same doctors at King's College Hospital offered me to start a new clinical trial for 3 months. This time the treatment was based on a combination of tablets (Sofosbuvir and Velpatasvir). I started on 6 December 2016 and I finished on the 2 June 2017. This therapy worked and my blood was cleaned.

2.30. Despite my recovery from Hepatitis C, the side effects were all still there. The treatment left me with headaches, not as bad as the ones I had during the first trial, but they were still strong. I have been taking so many medicine in these years that I had and I still have so many side effects, but I am not sure how they are related to each other, or which specific drug caused which effect.

Other Infections

3. In 2016/2017, after the liver transplant and while I was doing the second clinical trial the doctors found out that I had a marker for hep B. Since then I have been prescribed some tablets to cure the Hepatitis B and some other anti-rejection medicines. I will have to take for the rest of my life.

Consent

4. I have been asked whether I always gave consent to the treatments or the tests they did on me. I am perfectly aware that for some procedures

you must give consent while for some others, like in theatre during surgery you cannot. The doctors always asked for my consent and explained to me the procedures and options. They were all really very nice. For example before the liver transplant the consultant fully explained to me the whole procedure in details.

4.1. Sometimes I also had the feeling that they were not that bothered to give me as many details as they normally give to the other patients. But I think that this is because I am a fully trained nurse, I know the procedures, what to do and the risks. I remember that once a doctor told me "Marie, you know it all, but if you have any pain or discomfort you must tell the nurses".

Impact

5. I am alive and this is the most important thing, but rather than living it feels like I simply exist from one day to another. Sometimes I do find it difficult: I forget things or people's faces or I remember the face but I cannot put a name to that person.

5.1. Because of all that I have been through I still do have my discomforts, I feel a bit lethargic at times, I have headaches and I have to take some tablets to feel better. My back hurts so I can't lift heavy things and if I go out I can't sit down for a long period in one place, I have to get up and walk around, even on airplanes.

5.2. Recently I feel "a little bit under the weather" and I get tired for no reasons at all. Before I used to cook and to take care of everything at home. But now I can't, my husband has to do it, he's really very good especially considering that he was the kind of person who never had done anything by himself, not even a coffee or a tea. I was doing everything but things have completely changed now.

5.3. Before the transplant I started to have blackouts and I still have them now. As a result, I have no confidence and don't go out on my own anywhere. Even if I go to the toilet, every now and then, all of a sudden everything becomes dark. Once I literally fell down and passed out. I also passed out in the shopping centre and ended up in West Middlesex University Hospital. I told the doctors and specialists that I have been having these feelings, but nobody has been able to give me an explanation.

5.4. Soon after the transplant in 1995, the doctors prescribed me Prograf, which is an immunosuppressive drug they gave me after the liver transplant to lower the risk of organ rejection. Because of this medicine I developed Type 2 Diabetes. Luckily I don't have to take any insulin but I will have to take tablets for the Hepatitis B and the immunosuppressant for the rest of my life.

5.5. Since the transplant I started to feel pain and discomfort in my right shoulder. At first I thought it was a form of pain related to the surgery to the liver, but when I mentioned it to my GP she said that the pain was related to a problem with my heart.

5.6. So the GP referred me to another consultant at King's College Hospital who found out that my aortic valve was seriously narrowed and that they had to put a valve to fix it. I had to undergo a couple of bypass surgeries and due the medicines I was already taking they couldn't use a metallic valve and they opted for a tissue valve.

5.7. I am not sure whether these heart problems are related to the Hepatitis C, the problems with my liver or to the transplant. No one ever gave me an answer.

5.8. As I explained above, to cure the Hepatitis C they initially tried to give me Interferon and Ribavirin. That therapy was hard, I was struggling a lot and the side effects were really bad.

5.9. Even the GP, during one of the visits, he looked at me and he told me that if I was struggling too much, we could have stopped the therapy. I tried hard to resist and I took the 2 medicines for 2-3 months.

5.10. The side effects were loss of appetite and loss of weight. I couldn't eat and my body, despite the fact that I never had backaches and things like that was aching. Even now my whole body is aching and I don't know why. It's horrible to experience the feeling that sometimes I have to stand by the stove for a while, or sometimes in one place and I cannot do anything because I feel I am fainting.

5.11. They prescribed me the complete course of the injections and I finished both injections and tablets. I used to do my own injections, it was so hard. I am a trained nurse, I know how to do it but it was so difficult to inject myself. After the 3 months I was feeling ok, a little bit better from the physical point of view.

5.12. With the second clinical trial in 2016-2017, there were side effects from the treatment but as I said above they were not as bad as the other ones. Headaches mainly, but definitely not as bad as the previous ones.

5.13. I have been asked whether my status of being infected with Hepatitis C had an impact on my dental care. I told the dentist I have Hepatitis C. Around 2000, I needed one of my teeth to be extracted and the dentist did say he would rather have the hospital to do it as he didn't want to touch me and even the hospital didn't want to remove it because of the Hepatitis C. I can understand their reaction and I was fine with it. In the end a doctor at the West Middlesex University Hospital did it.

5.14. My condition had a strong impact on my family. My husband had to retire to look after me because I wasn't well. He didn't need to retire; he could have carried on working. The fact that he had to give up his job to take care of me, affected us a lot, both personally and financially.

5.15. The kids have definitely been affected, although they don't outwardly say it. My daughter says that she couldn't go out with her friends, as she had to look after me. It was difficult to console them or advise them on different things. Once, for example, while my daughter was doing her O level exams, she came home after school and she found me collapsed on the floor. And it happened again, not that long ago when I went to the toilet and I was coming out, I felt I was fainting and I immediately needed her help.

5.16. Things and episodes like these, affected my kids badly. They still have problems; my daughter thinks she took more responsibility that what she should have done and my son thought that he had to look after his mum. These are not the kind of things that normal kids should think of their mum. But I cannot do anything to change the situation.

5.17. My family and our close friends do know what I have been through and they have been understanding. I wasn't too happy to tell them about it but I thought I had to tell the truth. If my husband is not around someone needs to help me and I cannot keep it secret and risk that something bad happens. My daughter and my son know it as well. My son rings me everyday, asking me how I feel or what I have eaten. He is behaving like a mum. This is not right, it is very frustrating but I cannot do anything.

5.18. I completely stopped working at the beginning of 1996. At that time I was working for the social services in Hounslow and I was in charge of care homes. Because of my training I was actually the only SRN to do medication. I enjoyed working as a resident social worker in some respects, I still preferred doing medicine though. And every now and then when I think about it, I miss it. When I had to give up this job, it was terrible for me. It affected me quite a bit.

5.19. To be clear, I didn't stop working because I wanted to, but because I had to. After the liver transplant, when I went for a check at King's College Hospital the usual consultant found out that I was still working and he told me that I could not do it because people in my condition and with liver problems need to rest and cannot work. I didn't take him seriously. But 3 days after I went back to work at the social services, the management called me and they wanted to talk to me. I was really worried that I did something wrong or that I gave the wrong medications to some of the patients.

5.20. I could have never imagined that they would have asked me to go on medical retirement. But that was what the meeting was about. The consultant from King's College Hospital after warning me in the hospital, wrote to the management, a letter saying that at as of now I was not able to take the responsibilities that my work normally required. The specialist also wrote that if I had worked again, he would have taken action against the council. They showed me his letter but I didn't read it.

5.21. At that time I was not even 50 years old. It took me over four months to come to terms with the retirement. It was really hard. I was quite upset and I kept arguing because I have always worked and I knew it would have been very difficult. I became depressed and my GP prescribed me some antidepressants. I am still taking them, some milder ones but they help me to cope with it.

5.22. My employers told me that I would have got used to it. Colleagues even told me that I was fussing too much and that some of them were waiting for medical retirement as it adds 6 years to your retirement. Even the union representatives told me that I should have been happy to get medical retirement, so I could have stayed home. But I wasn't happy at all.

5.23. I tried many times to rationalise their decision. I think that because I was a nurse, they were afraid that I could have infected someone. I was not angry with the consultant and his letter but I was really sad and disappointed that I had to leave my job.

5.24. In certain respects, when nowadays I think about it again I think that they did me a favour, because of what he did and because of the letter he wrote, I am here today, safe. Complications could have come and maybe I could have done something wrong. Considering my condition I don't think I could have kept up with all my work responsibilities and to normally deal with life and death on a daily basis.

Treatment/Care/Support

6. If I look back to all I have been trough in these years, I can still say that I am doing fine. I think that I can't complain about the medical treatments I received. From the top person to the bottom one everybody took care of me. When I think about it and I think back to what the consultants told me and how they treated me, I remind myself that people have been waiting for years to have a liver transplant and there were people coming from abroad and people spending thousands of pounds while I have been treated so well by NHS and so quickly.

6.1. I had access to all the treatments and medications with no problem at all. Until I was diagnosed as diabetic, I had to pay for all the medication as I was not exempted, but everything was fine.

6.2. In relation to psychological support, I had been offered some counselling from King's College. I did have some meetings and I think it was enough for the time being. When the nurse discharged me after the transplant, I felt fine but then I started to forget things and to get a bit nervous. They didn't suggest counselling when they put me on medical retirement. Now I think that perhaps that would have helped a little bit more. I was and I am still taking some antidepressant.

Financial Assistance

7. I found out about the Skipton Fund from a friend who had read about it in the newspaper, The Times. Following this suggestion, we prepared the application. We had to fill in a lot of information as they asked for a lot of details and I remember that one of my consultants had to endorse the form. But the application ended up to be successful at the first attempt.

7.1. I received a one-off payment of about £40,000 and after that I started to receive the monthly payments. During Tony Blair's government they said it was an ex gratia payment and that would be all. They said that I would have got one final payment. But after that they started to make monthly payments again. In 2013 I also received two other lump sum payments of about £25,000.

Other Issues

8. I am not involved and I have never been involved with any campaigning, inquiry or group litigation.

Statement of Truth

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

Signed GRO-C

Dated 1-11-2018