Witness Name: Elisabeth MICHEL
Statement No.: WITN0057
Dated: 06/03/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ELISABETH MICHEL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6 March 2019.

I, Elisabeth Michel, will say as follows: -

Section 1. Introduction

1. My name is Elisabeth Michel. My date of birth is GRO-C 1959 and my address is known to the Inquiry. I am single and have a son who was born in 1981.

2. I intend to speak about my infection with Hepatitis C (HCV) as a result of receiving a contaminated blood transfusion. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.

Section 2. How Infected

3. It is my belief that I was infected with HCV in 1988 at Guy's Hospital, London SE1 after receiving a contaminated blood transfusion following treatment for leukaemia. The hospital is now part of the Guy's and St Thomas' NHS Foundation Trust (GSTT).

Background

4. I was diagnosed with acute myeloid leukaemia (AML) in GRO-C 1988 just a few days after my 29th birthday. I had a Hickman line fitted and started chemotherapy the day after entering hospital.

5. I was in hospital between April 1988 and 11 June 1988 for Chemotherapy. Throughout this period, I received daily transfusions that alternated between blood and platelets. The blood transfusion would happen on one day followed by platelet transfusion the next day and then blood again and so on and so forth. I mostly received AB+ blood. I remember one incident where I had an adverse reaction after being given blood. I started shaking uncontrollably.

6. About two months after the Chemotherapy on 11 June 1988, I was in remission and was discharged from hospital. Before the treatment I had a 55% chance of not pulling through.

7. My consultant, Professor Schey was trying a new treatment to prevent AML coming back. As part of this, I agreed to have an autologous bone marrow transplant.

8. The first part of the treatment involved having my own bone marrow harvested. This happened in September 1988 over two days at Guy's Hospital. I then went to St Thomas' hospital, London for Total Body Irradiation (TBI). This lasted three days and killed the remaining bone marrow.

9. On 6 October 1988 I then came back to Guy's to have the transplant. This process lasted three months and required my body to fabricate my own platelets again. I remained in hospital as I needed extra care – I would have bled like a haemophiliac if I was discharged and it would have then been more difficult to be able to be readmitted to hospital again (getting a bed etc.) – at least that's what I was told by Professor Schey. I left hospital on 21 December 1988.

10. The regime of alternate days blood transfusions/platelets started again from 6 October 1988 to 21 December 1988. As far as I know, I was given the transfusions and platelets to supplement what my own bone marrow was unable to supply while my blood cancer was being treated.

11. From the first transfusion I was never given any verbal or written warnings about the possibility of infection from blood. I never had a blood transfusion before this time. I remember seeing nurses/doctors using gloves when taking blood samples, however, I thought it was to protect themselves against patients who had HIV in their blood.

12. I remained under the care of the Haematology department at GSTT for the leukaemia and to check it was still in remission. I agreed to continue check-ups well after the 5 years blood cancer remission, because "I was part of a study by Professor Schey".

13. In 2006, I was not feeling well I could no longer digest some food like fish and chips. I had had pain in the liver region but dismissed it. I first went to my GP in June 2006 because something happened at work and I was off for stress.

14. Dr Rodrigues (now retired) questioned further how I was feeling and said I am sure this has something to do with Hepatitis C (HCV). I had not heard anything about it and so I did not believe him. He gave me more time off work to ensure I went for all the blood tests.

15. I then was referred back to the Liver unit at GSTT to do more tests and to find out the HCV genotype. I had a liver biopsy that pointed to genotype 1 but it did not give conclusive evidence of scarring for liver cirrhosis.

16. I was referred to a consultant who explained HCV and that there was a treatment that would last for one year (standard for genotype 1). I opted for it because after the leukaemia, I just was not going to face possible death without doing anything. He explained that I had probably been infected through transfusions. By this time my medical records at GSTT were very big files (around 2 folders thick) and this followed me around all the time.

17. I then went to the Clinical Nurse Specialist – Viral Hepatitis, Susan Johansen, and started treatment on 14 February 2007 by using Interferon and Ribavirin for 12 months. I was given a booklet explaining HCV and what side effects to expect from the treatment.

18. I started to attend a HCV support group held at the Hep C Trust, near GSTT, to get more information and to meet other people going through the same thing.

19. I, however, managed to find much better information from a French website about how to manage the treatment and I was able to share this with my parents and family in France. Compared to the UK, the info was 10 times more available and presented in an attractive layman's format with illustrations.

20. I think from the leaflets and my involvement with the Hep C trust I kind of understood how the virus could be transmitted. I did not share toothbrushes with my family and was alert to any bleeding injuries. My sister in law was HIV positive and died in 1994. This coupled with my ~~being~~ brother being a nurse meant as a family we knew how to be careful.

21. I believe that I should have been personally alerted to the possibility of infection as soon as it was discovered that it existed in 1992. My GP was told to look out for HCV and other blood born viruses, why not me?

22. The service at GSTT with the Clinical Nurse Specialist – Viral Hepatitis was well established and I was treated well by them most of the time. They gave me the results of tests in a way that I could always ask questions.

23. I was, however, shocked to have to pay when I collected my first prescription especially because I had been given the virus by GSTT. I previously didn't have to pay for the leukaemia prescriptions/treatment because I stayed in hospital for 6 months. A colleague at work had to explain how to pay monthly for the prescriptions because nobody bothered at GSTT's pharmacy.

24. During the treatment there were also some mix-ups. Sometimes I was short on Interferon because either someone had been given too much just before or it was Easter and I had to wait and go back the next day/week. It got sorted but it was a 4 weekly palaver to get the treatment.

25. My son's father died in January 2007 of a heart attack. He had liver cirrhosis (due to alcohol as he also drank) but since the 27-year relationship broke down late 2005 I did not know how to contact him once I knew I had HCV. I will never know how much of it might have been caused by HCV or if I had transmitted it to him since 1988, nearly 20 years earlier. I often think about it.

Section 3. Other Infections

26. To date and to my knowledge, I do not believe that I have received any infection or infections other than HCV as a result of being given infected blood to date.

Section 4. Consent

27. I was not given any information about blood transfusions especially about the possible risks of contamination. My first transfusion in April 1988 was done the day I arrived at GSTT in a very emotional state after being told that the serious anaemia was actually leukaemia. Apart from crying all night thinking I was dying, the conversations with the doctors were about what was going to happen with the chemo. The blood was part and parcel of a blood cancer treatment.

Section 5. Impact

28. Once I knew I had been infected with HCV, I felt unclean for years afterwards and started to take notice of all the things like insurance, travel and a possible funeral. All of which became complicated.

29. I was not angry because this would have not helped me. I had survived cancer only to be hit by something else, which was begotten as part of the treatment by the same hospital that was now treating me again, GSTT.

30. Luckily I did not have to look after my son who by then was 26 years old. He was doing a year abroad working in Korea so I had no immediate support. I had to explain things to my family in France who did not really understand why HCV was worse than any other hepatitis infections people sometimes contracted (my dad and brother had one ages ago (1955 and 1970s), A or B I don't know.

31. I travelled to France for holidays and to have a rest with my family. I remember I had my hospital letter with interferon syringes in a cooler bag. I feared that I would have to explain these to customs (never had to). I was tired all the time before diagnosis and knew what tired was from the leukaemia but this was different.

32. I did not have heavy liver scarring and the liver biopsy was inconclusive. I had many fibroscans (early) and the liver ultrasound (US) scans regularly. Nothing else actually actively related to HCV.

33. I had interferon and ribavirin for 12 months from 14 February 2007. Time seemed to go quickly after the diagnosis and it felt like I had to start the treatment – it was like start now or do nothing at the time. The Liver unit was efficient in processing patients.

34. The treatment was very hard but I managed to keep on working. I had a desk job in publishing so it was not physically demanding. I went to the library next door for a snooze at lunchtime because my employers were not particularly bothered or understood anything. I slept everywhere I could. I was very lucky I could function. Although the brain fog was acute I had no problems to attend all the appointments. I was cold very often but managed.

35. Mentally, I had regular appointments with a psychiatric doctor and managed. The state of being like an anorexic and having to force myself to eat was more difficult to manage. I could not tolerate much food or the smell of it. The treatment was hard as I had diarrhoea often (this still persists now) but the hospital did all diagnostic tests to rule out IBS. I could not get treated with an injection for a shoulder pain but got acupuncture instead. I got severe reactions with pustules at every site needles were put in because of the interferon.

36. I never said I was on treatment or mentioned my HCV to others. My social life was restricted because I was so tired.

37. I cleared HCV after a year of treatment so did not feel stigmatised because most of the time when I was infected I did not know. While on treatment, I was very careful to whom I mentioned HCV.

38. I became very irritable with the treatment and this has persisted. My parents noticed a change that was not there before. I know how to control that better now but it does not take very much for me to get rattled.

39. I kept working and was able to take sick leave when needed and apart from paying for the prescriptions for the treatment I did not have financial effects. I did not have a mortgage and avoided loans.

Section 6. Treatment/Care/Support

40. I did not have difficulties in obtaining treatment, care and support because it was very much part of the specialised work they did at GSTT and it seemed a well-oiled machine. I was obviously not the first patient (I met one victim at support group) and by the time I came along, GSTT had got their act together.

41. I received psychological support (psychiatrist regular appointments) as part of the treatment only because of the interferon side effects. I had no specific counselling between suspected diagnosis in June 2006 and treatment starting in February 2007.

42. I only had discussions with the consultant about "yes or no" would I like to undertake a yearlong treatment with many known side effects at the time. In between, I had been completely ignorant because when I heard about HCV and HIV contamination by blood transfusions, I thought only the haemophiliacs were affected. Since I had blood cancer I never thought it could happen to me. How naïve!

43. In summary, there was no specific counselling. I only found support when I went to a support group a week after starting my treatment.

Section 7. Financial Assistance

44. I was told by the Liver nurse to get in touch with the Skipton Fund. They made a £20,000 award in April 2007. Then nothing until new payments were made monthly in 2017 of £250. The Skipton Fund ceased to exist and was taken over by a new agency.

45. I did not have difficulties applying to Skipton because I was being treated at the same hospital where I got contaminated; GSTT had all the files. I just brought the paperwork to a consultant who filled, checked and signed them.

46. The Skipton fund were very helpful when the DSS stopped my dole money for 6 months because I told them about the award thinking they would look into my bank accounts. I had been made redundant in 2010 and fortunately I had redundancy money to use but it was like the DSS did not want to know.

47. The award I received was the minimum because the liver biopsy did not clearly indicate that there was cirrhosis. Even if I had had cirrhosis it would have been difficult to prove beyond doubt for the higher award, unless I had started to exhibit all the symptoms and was near the end of the liver life and more at liver transplant waiting list/stage.

48. When I received the money it was just a lump sum with no apologies or explanations why this was in place or advice on how best to use it. I felt that if my health deteriorated to a point I needed help, I would not be able to afford external help or treatment for a while. It appeared that the amount of money that was awarded seemed to be plucked out of thin air.

49. It was possible that I may not have lived until my HCV was diagnosed because I could have developed a secondary cancer (still possible). Then they would have never known about my contamination. I don't feel the award represents personal circumstances as it's the same for everyone

but the ongoing side effects of treatment differ for everyone and the award may not be sufficient in the long or short run.

Section 8. Other Issues

50. I asked for my medical records on 23.02.2019 as all my records from 1988 onwards are at GSTT (I will make an additional statement should relevant information becomes available). I really would like to know how many transfusions (poss.94) / platelets bags I had over the year 1988 and if the provenance was written. Also if there was any information about possible contamination and why no information was given.

51. I need the records to see how blood was allocated according to provenance for transfusions. Additionally, I would like to know if there was a policy making a difference between cancer patients and other patients needing just a one-off blood transfusion. Also I would like to see if there was anything like a policy about giving blood cancer patients contaminated blood because, as they required so many blood bags, if they died of cancer or transfusion it would not have made much of a difference.

52. Although it is claimed contamination was not known at the time (nor HCV pre 1992) cancer patients could have been allocated contaminated blood because of the immediate health benefits by extending their life. Statistically there was a chance of them dying before they developed any of the illnesses linked with contamination like HIV, HCV or anything else. This should be investigated.

Statement of Truth

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

Signed GRO-C

Dated 18/03/2019