Witness Name: Michael Michael
Statement No.: WITN39250001
Exhibits: Nil
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MICHAEL MICHAEL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 January 2020.

I, Michael Michael, will say as follows: -

Section 1. Introduction

1. My name is Michael Michael. My date of birth is GRO-C 1964 and my address is known to the Inquiry. I am married and have two children.

2. I can confirm that I have chosen not to have a legal representative with me at my interview with the Inquiry Investigators on 13 January 2020 and that I am happy for the Inquiry team to take my statement.

3. I am thalassaemic and require regular blood transfusions to manage my condition. It was via one of these transfusions that I contracted Hepatitis C. I intend to speak about how my life has been impacted by contracting this infection, and especially, how its treatment has affected me.

4. First, I will provide some background information on thalassemia; both personal and general. I will discuss Beta Thalassemia, my condition, caused by two abnormal 'carrier' genes being passed down from my parents. It means my body makes less haemoglobin than necessary and I need blood transfusions to survive. Alpha thalassaemia is more common in South East Asia. It is a more serious variant, with Alpha major, any child will die in the womb, or a few hours after birth.

5. Thalassemia treatment is via blood transfusion, as the blood cells do not last long enough. It also puts the bone marrow under strain, causing the bones to expand. To suppress the bone marrow, regular transfusions are needed every four weeks. I need between three and four bags of blood by volume. This takes about two hours per bag to infuse.

6. People originating from the Mediterranean, the Middle East, Africa or Asia may carry some form of thalassaemia gene (a carrier rate of one in four to one in seven depending on your ethnic origin) but it's rare in Northern Europeans (carrier rate of one in one thousand). There are two types of beta thalassemia that need medical treatment. In order of severity they are: thalassaemia Major, and thalassaemia Intermedia. Here in the UK we currently have 1000 registered beta thalassaemia patients being treated both major and intermedia.

7. Many hospitals now have a specialist thalassemia unit, the Wittington Hospital, London (The Wittington), where I currently receive treatment, has such a unit. I used to be treated at St Bartholomew's Hospital where I received the infected blood. There have been different versions of blood used in my treatment and some have performed better, for example, whole blood or leukocyte-reduced blood transfusions. Some produce worse reactions than others. I remember one product, in particular, causing itching of the hands. Current practice requires that the haemoglobin be as fresh as possible, so the blood bags we get are normally up to seven days old.

My thalassaemia

8. My parents are from Cyprus. They both immigrated to the UK where they meet and married and I have one younger brother. At 16 months old my parents noticed I was not growing as I should and was eventually diagnosed and treated for Beta Thalassemia Major at St Bartholomew's Hospital, London (St Bart's). You have to have a 'bad' gene from each parent to inherit thalassaemia. I got both 'bad' genes and my brother got the 'good' ones.

9. My parents are carriers (Beta thalassaemia carriers are healthy and do not know that they are carriers unless tested). Less severe, but not by much, is the beta thalassaemia intermedia category (they may at some point go towards a transfusion dependent regime). The most prominent thalassaemia is my group (the beta thalassaemia majors). At the time of my birth, the life expectancy for a child born with my type of thalassaemia was 16 years.

Section 2. How Infected

10. I was infected with Hepatitis C prior to 1990. I believe it was between 1986 and 1990. As a thalassaemic, I received blood transfusions frequently and cannot pinpoint the exact transfusion responsible for my infection.

11. I was told at St Bart's in the late 80s to early 90s. It came totally out of the blue. I went in for my normal tests and my consultant at the time said I have Hepatitis C and not much else. They told me it was a liver condition. It did not seem like a major thing.

12. Around a year later, I was told more formally that I had Hepatitis C, but there was no treatment. It was again termed as a liver condition.

13. I was about 28 and I glossed over it as I was barely told anything. Only my partner and the dentist knew.

Section 3. Other Infections

14. I did not contract any other infections as a result of my transfusions.

Section 4. Consent

15. As thalassaemics, our health is constantly monitored. But I do not recall being specifically tested for Hepatitis C until I got to the Whittington.

Section 5. Impact

Physical impact of the Hepatitis C infection

16. In terms of the effect of the Hepatitis C itself, there is nothing that I can pinpoint. Separating out the initial symptoms from the thalassemia is hard as they are quite similar in terms of fatigue. There were no clear warning signs. It was the treatment, more than the infection itself, that had an immediate effect on my health.

Physical symptoms of the Hepatitis C treatment

17. I was told there was no treatment available when I was first diagnosed. I began Interferon in 2001which cleared it but four months later it came back. It took more than ten years to eventually clear the infection.

18. In 2003/2004, I went on a combined round of Interferon and Ribavirin. There was a gap as the side effects were so severe. I was on the combined treatment for six months. Once again, I cleared the infection, but the infection returned.

19. In 2014, I received a trial drug which cured it. I was treated at the Royal London Hospital and had no side effects at all. I only agreed to go on these drugs once I was assured there would be no side effects as I had such a terrible experience previously.

Physical side effects

20. The side effects I experienced were not only hard at the time of treatment, but have had a long-term deleterious effect on my health. At the time, I suffered the following: fever, sweats, weight loss, joint pains, exhaustion paranoia and depression.

21. On the exhaustion, during my first two rounds of treatment I did not want to get up in the morning, especially the morning after the treatment, which was three times per week, in the evening, before bed.

22. I knew this tiredness was not thalassemia related, as I would be tired three days after my blood transfusion, rather than the usual four weeks. We usually feel tired as we go towards our next transfusion, that's a cycle I have had since I was 18 months old, so I know the difference. This was a different kind of tired.

23. The treatment literally trashed my blood cells. I was going in every two weeks, for eight bags, instead of the usual four, but this led to a build-up of iron in all my organs especially the heart and the liver. This added extra stress on my heart and aggravating the damage to my liver. All these effects with the Interferon plus the usual blood burden.

24. Iron overload is a major concern for thalassaemics. Currently I need to take chelation drugs to lower my iron levels. This used to be Desferal by injection 12 ml every night (8 to 12 hours which was administered by a battery powered pump). My current regime is Ferriprox and Exjade, a combined 18 tablets a day.

25. Whilst I was on Ribavirin the only chelation drug I was allowed was Desferal. I could not increase the dosage as it had to be administered over a period of eight hours to twelve hours and is toxic.

26. Before, during and after my treatment I had to have liver biopsies to test my iron level. It is a horrible procedure that has a 1/1000 chance of causing death but was the only way they could tell how much iron was in my system and to assess how the Ribavirin was affecting it.

27. Thalassaemics are very precious about their veins and my veins were also trashed. We have 'preferred' veins and whilst I was being treated it got to the stage where someone was trying to cannulate me and eventually managed on the seventh time. There were bits of blood and bruises everywhere.

Mental side effects

28. Ribavirin compounded the problems I had on Interferon; every day was a struggle. I literally could not get out of bed. My haemoglobin level runs between 10-13. A normal person's is 13. On the Ribavirin, it would be at 8 ½, never higher. I could feel my spine and pelvis pulsate as my bones attempted to make more blood. The pain made me tired and irritable. On top of this, the Interferon caused me to become depressed, to the extent that I had anxiety attacks and suicidal thoughts.

Long term physical damage

29. With my body unable to get rid of the excess iron, my soft organs were permanently damaged. Specifically, the liver, heart and pancreas.

30. My liver iron before the treatment was 12,000 (a normal person is 300). We, as thalassaemics, try and reach 600 normally. Eventually it went up to 20,000. The structure of the cells is permanently altered. Now, with years of monitoring and treatment, my clinicians have been

able to lower my iron count to 7000. My liver is still loaded but we are working on getting that down. The cirrhosis is also worsened by the high iron levels.

31. As for my heart, the heart can't tolerate that much iron and I went into heart failure.

32. All these effects remain with me. My diabetes and insulin use is only now reaching acceptable levels and is coming down thanks to the aggressive use of both iron chelating drugs reducing the iron loading in my liver. The thing is, we just don't know. Thalassemia was always a childhood disease and my generation are the first to live this long.

Working life

33. Getting up at six in the morning, cold, tired and sweating and commuting into central London was incredibly depleting. Back then, working from home was not an option. I would have to sit in a hot bath in the morning to let myself warm up. Once I got to work, my colleagues would 'get it in the neck', which was out of character for me.

34. Luckily, I was the boss at that time, so there was some flexibility. Overall, if nothing else, the experience taught me to be more tolerant of my colleagues

Financial effects

35. I was very lucky in that work was understanding initially. I have always tried to be give and take. Unfortunately, I had to quit my most recent job because they were docking my wages every time I would have an appointment and it became unworkable.

Stigma

36. I have definitely felt it. It is one of those things where, it is not as bad a HIV, but always, for example at the dentist, you feel like you have to decide whether to tick anything about infections.

37. There is also the stigma attached when going into a new relationship; how and when do I tell them, how will they react, will we have a normal relationship?

Section 6. Treatment/Care/Support

38. Support was not available. I told them that I was suffering mentally but there was nothing offered to me at the time.

Section 7. Financial Assistance

39. I receive some money from the Skipton Fund. I received the initial payment in 2017. For level 1 cirrhosis you receive £20,000-£30,000. Personally, I currently receive £30,000 annually at three-month intervals (approx. £8,000 every three months)

Section 8. Other Issues

40. I think I can offer some insight into why there are only a few thalassaemics who have made a statement to the Inquiry. Our parents were told we would only make it to our teens. This mentality leads to compartmentalising and trying to show everyone they are wrong.

41. When you're growing up as kids, you want to enjoy life, you want to play football and not think about your condition. So, a lot thalassaemics end up not taking their drugs and not taking care of themselves.

42. I think you'll find that they don't come here as they don't want to deal with it anymore. The mentality is, if I am cured now I do not want to revisit it.

43. Also, as a Greek Cypriot in a small community, people what you have and we deal with things internally. I had to face death from a young age and how we deal with death is very strange. So maybe that has affected our community's approach.

44. I used to be the President of the United Kingdom Thalassaemia Society. It could be useful for Romain Maharaj, who is the Executive Director, to write to people and ask if they have Hepatis C, so that there can be a better idea of how it has affected us.

Statement of Truth

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

Signed GRO-C

Dated 17th March 2020