Witness Name: Nahidur Rahman
Statement No: W7424
Exhibits:0
Dated: November 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NAHIDUR RAHMAN

I, Nahidur Rahman will say as follows:-

Section 1. Introduction

1. My name is Nahidur Rahman. I reside at GRO-C London, GRO-C My date of birth is GRO-C 1988. I live with my father, my wife and 2 children. I work full time in PR.

2. This witness statement has been prepared without the benefit of access to my mother, Sultana Chowdhury's full medical records.

Section 2. How Affected

3. My mother was infected through a blood transfusion she had in 1987 following the birth of my older brother at Newham General Hospital which is now part of Barts and London Trust.

4. As a result of the blood transfusion, my mother got Hepatitis C and became a haemophiliac. She was initially diagnosed with Hepatitis C and very soon after with liver cirrhosis. She was then told she had a Factor 11 deficiency as

a result of the damage to her liver. She was also given tranexamic acid to help to prevent her from bleeding.

5. There was a big gap between my mother being infected in 1987 and being diagnosed with Hepatitis C in 2011.

6. Newham Hospital no longer had my mother's records when we requested them, however we were able to locate some archived GP records and the discharge summary confirmed the blood transfusion. From my understanding it was given to her very rapidly. My father had just left from visiting her after the birth of my brother and my grandfather went to take over from him and visit. While my grandfather was there it was given to her very rapidly, he was told they needed to do it so he told them to do what they thought was best.

7. No information was given as it was given rapidly.

8. My mother was infected with Hepatitis C (HCV) as a result of the blood transfusion.

9. My mother found out about her infection in February 2011 when she tested positive for Hepatitis C antibodies.

10. My mother was given information, a combination from the GP and the hospital. In October or November 2010 she had her appendix removed and had had abdominal related issues for a number of years before her diagnosis with Hepatitis C. She was always told she had gynaecological issues. She had a hysterectomy a number of years back, and in 2010 had ovarian cysts. It was just a matter of her going back and forth between the GP and the hospital for all of these various issues and someone down the line did the test for Hepatitis C.

11. In hindsight, she did have a lot of symptoms. She started to have a lot of problems after she had been given the blood transfusion. One of her finger nails died and she started to have a rash all over her body. She had a lot of

rashes in the 90's. She also had all sorts of abdominal/gynaecological issues. I do not know if those issues were caused by the Hepatitis C.

12. My father was with her when she was diagnosed and they told her that she had got Hepatitis C, they didn't know how she got it perhaps it was when she was younger in GRO-C

13. We had no idea there was a link between the blood transfusion our mother had and Hepatitis C until a consultant mentioned the Skipton Fund and that triggered the memory that she did have a blood transfusion and that started our search for the records.

14. My mother was not provided with adequate information to help her understand and manage the infection.

15. English was not my mother's first language. Her English was good enough for her to get by on a day to day basis but when it came to technical things, such as medical conditions she would not have been able to understand and digest the information at a level she should have been able to. At that time my parents had no idea how to use a computer, so there was no opportunity for them to look anything up. We knew the seriousness of her illness, but what we did not know until 2017 was the level of cover-up and how many other people had contracted Hepatitis C via the NHS

16. The information was given to my mother very poorly and without much guidance. The GP was not very good, that is why she moved surgeries, the GP just used to tell her to go to A&E, she felt helpless. She would have moved surgeries before but because of Covid she was out of the country abroad for 18 months. The only good thing the old GP did was to have the records in archives as the level of care they gave her was poor, this is why her diagnosis was so late. She visited the GP so many times and any symptoms were totally overlooked.

17. My mother was not given enough information about the risk of infecting others, or not at a level she could digest and understand it. English was, as I have said, her second language and was not at a good enough level to

understand any sort of leaflet about a medical condition. She was not given the information in a format accessible to her. She knew a little about transferability because of what the doctors did tell her, the doctors told her no one would get it from using the same utensils, that was about it.

Section 3. Other Infections

18. As far as I am aware my mother did not have any other infections as a result of the blood transfusion.

Section 4. Consent

19. I don't know if my mother was aware she was having a blood transfusion at the time, my father was not there, my father had just left and my grandfather took over and consented to it, telling them to do what they needed to.

Section 5. Impact of the Infection

20. The infection had a massive impact on my mother's mental health. She was depressed and dependant on anti-depressants. She was on them for a long time from her initial treatment towards the end of 2011/2012. She would get angry at us really easily and would be really tired. She would have real highs and super lows. Her energy levels were impacted, at times she would be able to do things and others she would not be able to.

21. At the time of the diagnosis she had 3 grown men to look out for, my father, my brother and myself, her motherly instinct was to do things for us even when she was ill.

22. In my late teens I started learning how to cook, and my father cooked which meant we didn't have the mother we should have had because of the infection.

23. It was difficult for people to understand her highs and lows, she would get angry, the problem was her illness was not visible to others and in her mind she had to try and justify being unwell. Even though we understood, she felt like no one would understand and that made her really upset.

24. When she didn't feel well, her response was to go to her GP, but she felt like the GP fobbed her off and she became more depressed after visits to her GP. Her GP instead of helping her would tell her to go to A&E but she would not get any help there either.

25. My mother tried to be the best mother she could, but her mental health state prevented her from being the mother she wanted to be. She had lots of side effects from the Hepatitis C, she had many of them before her diagnosis and quite a while before she was diagnosed. One of her problems after the blood transfusion was she had started to gain weight and could not pin point the reason for this. During the treatments for her Hepatitis C she had to take protein medications which made her more bulked up and this caused more depression. She lost her sense of taste so her spice tolerance went high, then would fluctuate. As a result of her symptoms her diet went really bad, her mobility was bad. She was a very small lady but she became very big in the last 5 to 10 years of her life. She wanted to exercise and lose weight but it was a vicious cycle because her energy levels were low due to the liver problems and she just couldn't do it.

26. As far as I am aware, my mother did not face any difficulties or obstacles in accessing medical or dental treatment other than the issues she had with her GP described above. I think the last treatment for Hepatitis that she had was in 2018 and after that they said there was no other treatment options available at that time and she was not a candidate for a liver transplant due to being overweight.

27. My mother was a housewife and in 2008 she decided she wanted to let us grow up a bit for ourselves and get out of the house so she did various courses in English, Health and Hygiene and ended up having a few jobs she

worked in Sainsburys, in Asda and then for the Council doing a bit of social work with disabled kids who needed transporting to and from school. She would help them on and off the bus. She was thinking about herself at this point and how she could improve herself in terms of her livelihood.

28. She then started to feel unwell and did not have a great end to 2010 she had to stop work as a result of the appendix surgery and then in early 2011 she received her diagnosis. She wanted to go out and have a level of independence and try and achieve personal goals, but she really couldn't do it, she was prevented from doing it by her illness.

29. At times she would not want to out or socialise, she struggled to walk long distances which prevented her from doing things she wanted to. Initially she coped ok, but as the years went by and her mobility levels were dropping she went from being independent to being dependent on us.

30. The only reason we lived in my parent's house was because I was one of my mother's carers, I was simply never able to leave home. We all had to sacrifice a fair bit to look after my mum. Her symptoms would fluctuate crazily at times. If someone who didn't know her would see her they would wonder what is wrong with her, they wouldn't understand that sometimes she could walk to the shops yet others she could not.

31. My mums social life was affected she could not go out with her friends, they would come to the house to visit her. When she did have to go anywhere myself of my father would have to driver her as she was unable to use public transport.

32. In 2018 when she was told there were no treatment options she decided to visit Bangladesh, the first time she went she really struggled because of her weight so when she did travel it would cost her extra money as she would travel business class to have more space and could keep her legs elevated as she would have fluid retention. The flights were a lot more expensive but we wanted her to be comfortable.

33. Before all of her problems my mother had an active social life. My father was the elder son of 8 or 9 siblings, so in our culture, she was the lady of the household among the siblings, it was always our house that was the centre point of family gatherings. Our culture is all about servitude, helping the family. Family gatherings were a focal point and throughout the years this gradually reduced to nothing because of her health. She enjoyed hosting every weekend, keeping people happy. When she was no longer able to do that she became unhappy.

34. I cannot remember her being normal now, for such a long time before her diagnosis her problems were being dismissed as "lady problems" when clearly there were more significant problems going on with her liver due to the Hepatitis C infection.

35. There was a lot of stigma in the community up until people knew that the infection was not transferable unless there was blood contact. Lots of people would no longer want to visit her. She felt guilty as well as she knew the parameters of her illness. I think the stigma in our community would have been worse had she been a man, being a housewife, she was never out on her own. If it had been my father who was infected the assumption would have been he was promiscuous. So the stigma was bad, but it could have been a lot worse.

36. My mother's infection had a big impact on me. I felt desperate for my mum to see grandchildren so I ended up getting married early in 2012. I didn't know how long she would be around for and so sacrificed my independence to give her grandchildren. My wife has made sacrifices too, all our married life she has lived with my parents. I did not have the independence I would have, when I went to university instead of going to one away from home I went to a local one so I could be there for my mum. My father took early retirement in 2019 and became my mother's primary carer. Her mobility was not good, she was getting worse and was cared for by my father my wife and I, we were her permanent carers. It was a difficult time for the whole family.

Section 6. Treatment/care/support

37. My mother encountered difficulties getting a diagnosis due to the way she was fobbed off by the GP. When she was diagnosed she was treated appropriately.

38. No counselling or psychological support was ever offered to my mother or our wider family.

Section 7. Financial Assistance

39. My mother was told about the Skipton Fund by a Consultant at Hospital in 2017 and it took until October or November 2018 for her to get on the EIBBS scheme. The issue we had is we assumed the doctors would know she contracted the infection from the blood transfusion but unfortunately somewhere down the line it was put in her notes that she possibly contracted Hepatitis C from her time when she was young in GRO-C I had never looked into these notes and had I done so would have flagged it up, we are GRO-C If my mother was not GRO-C GRO-C this assumption would not have been made.

40. We then had to try and prove that she caught the infection in the UK. Luckily my mother's old GP had some records from around 1986 to 1988 which showed when she joined the practice she did not have Hepatitis C, and confirmed the fact of an April 1987 blood transfusion post child birth. These documents helped my mother get onto the EIBBS scheme and she received the stage 1 and stage 2 payments.

41. My father was just accepted onto the scheme recently as her bereaved partner.

42. Initially the application process was super difficult, it was like fighting against a brick wall with all the information we needed to try and provide. It was much easier this time round for my father to get accepted onto the scheme.

Section 8. Other Issues

43. I think there has been a lack of accountability and mismanagements of patients and this is awful. Accountability is a big issue, no one is standing up and saying we made a mistake, there was a miss management of data and records, it has been nothing but a cover up. Had my mother's hospital records not been destroyed the NHS could have made contact with my mum to screen her for Hepatitis C years before she was diagnosed and perhaps the treatment, if she had received it then, might have been successful in clearing the infection, she might have been cured. It took from 1987 to 2011 for my mother to be diagnosed.

44. There was a lack of care, even when she was dying, she was treated poorly. She was in hospital for a month and a day before she passed away and there was a complete lack of ownership for her care. She was on a respiratory ward, but her care was being given by the hepatology team. The doctors passed the buck from one to the other, no one gave her the level of care she should have had. Her lungs were filling with fluid, she was struggling to breath. You do not expect this to happen in this country, a third world country, if in Bangladesh, a developing nation this stuff could happen, but not in the UK. My mum was a shining member of her community who went out of her way to better herself, she educated and empowered herself to get out to work and not be a typical GRO-C housewife, the Hepatitis C infection then took that away from her.

45. I believe my mother would still be here if she had had proper care. She was taken off important diuretic medication in June 2022 which caused fluids to build up, flooding her internal organs. Had her medication not been stopped

this would not have happened. Fluids were drained in the past and never got to her chest before.

46. Mum had returned from Bangladesh on the 12th of June and she was poorly so we took her to hospital on the 13th. The hospital gave her Vitamin K and increased her laxatives but stopped her diuretics. She was discharged on 16th of June and we were told she was in palliative care for 6-12 months, that was the first we were told we could potentially lose her, that was a bombshell, we were in shock so we didn't question why her medication was withdrawn. We were told her decompensation of liver would be managed with antibiotics, blood testing and monitoring and to take her to A&E if she remained unwell.

47. She became unwell so we took her back to hospital and in my view the treatment she received accelerated her death.

Anonymity

48. I do not wish to remain anonymous.

49. I do want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 20/11/22