Witness Name: Anna-Marie Smith-Clark Statement No.: WITN0754001 Exhibits: WITN0754002 Dated: 22.05.19 INFECTED BLOOD INQUIRY WRITTEN STATEMENT OF ANNA-MARIE SMITH-CLARK I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 02 May 2019. I, Anna-Marie Smith-Clark, will say as follows: -Section 1. Introduction 1. My name is Anna-Marie Smith-Clark. My date of birth is GRO-c 1985 and my address is known to the Inquiry. I am a married woman and the mother of three children (one daughter and two sons) and work as a consultant for the weight loss company "Weight Watchers". My mother died on 15 October 2000, when I was 15, from Hepatitis C infection, due to receiving infected blood as part of a blood transfusion. She was 37 years old. 2. I intend to speak about the circumstances in

mother

contracted Hepatitis C, the impact it had on her and the impact that it had on our family. I have also been asked about other matters related to

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which

discovered

she had

my mother's infection by the Inquiry Team and I provide my response via this statement.

Section 2. How Affected

- 3. My family are part of the traveller community and prior to my mother's death we lived in a caravan in traveller's sites and spent time travelling all over the UK. I am the middle child in the family and have one older sister, Mary, and a younger sister, Lisa. My mother was married to my father, Joseph Smith (also deceased).
- 4. My mother received a single blood transfusion in January 1980 at St Peters Hospital, Chertsey. This was following a still birth during which she experienced blood loss. The pregnancy was full term but there were complications during the birth and the baby was unfortunately still born. This was my mother's first child, born before me and my two sisters.
- 5. Until my mother's diagnosis with Hepatitis C everything seemed fine. She experienced no symptoms until around September 2000 to my knowledge. However in that month she suddenly became tired and started developing jaundice. Her eyes started to yellow and it was at this point that my mother and father realised something was wrong. I recall that we were travelling around Kent at this point but my father drove my mother to St Peters Hospital immediately as mum wanted to be seen in a hospital she knew.
- 6. At the hospital doctors carried out a number of tests, including a test for Hepatitis C and a test of my mother's liver function. The doctors discovered that my mother's liver was severely damaged and was failing as well as many of her other internal organs. The cause of this was found to be Hepatitis C infection. This was a big shock for the entire family.
- 7. I do not have any further knowledge of the exact circumstances in which my mother was

informed that she had Hepatitis C and cannot therefore comment on the adequacy of the information provided by doctors or the manner in which the results were communicated to my mother.

- We had never heard of Hepatitis C before this point. My mother could not read and write and was not well informed about medical matters. I recall my father being asked whether my mother had taken drugs. We were quite taken aback by this question as a family as drug use acceptable within is not the traveller community. My father reassured the doctors that his wife would not have taken any intravenous drugs. My ruling this out as a cause doctors concluded that the infection was due to receiving infected blood.
- 9. Prior to my mother's diagnosis, we had not received any information that would have led us to suspect that my mother was at risk of Hepatitis C infection. We had not even heard of the disease, let alone the ability to test for it. By the time we found out that my mother was sick it was just too late.
- 10. To my knowledge my father was not given any information regarding the ways in which Hepatitis C can be passed between family members. He was not given advice regarding testing for Hepatitis C. Accordingly my mother was the only member of our family to be tested.
- 11. As far as I am aware my mother was not informed of the risks of being exposed to an infection as a result of the blood transfusion. If this information had been given to her it would not have been such a surprise when she became sick. We would have known what to watch out for and would have made the link between the infection and the blood transfusion much more quickly.
- 12. My mother was admitted to St Peters. She was in and out of hospital during the first week after her diagnosis but was in hospital more than she was at home. She began to lose her

memory and experienced hallucinations whilst at St Peters. On occasions she was violent and tried to escape from the hospital. Because of this the decision was made to move my mother to a specialist liver unit in Kings College Hospital where she spent the last two weeks of her life. We were called to St Peters hospital just before the planned move as the hospital felt that mum would not have long left to live. However she pulled through and was moved as planned.

- 13. I visited my mum on three occasions with my older sister whilst she was staying at Kings. My younger sister was only three at the time and so stayed at home. My father visited my mother every day that she was in Kings. My mother was calmer when she was in the liver unit, presumably because she had been given medication to calm her down. Her memory returned and she was able to recognise her family members.
- 14. Due to multi-organ failure my mother began to gradually deteriorate. As a 15 year old witnessing this I could not believe that this was happening to my mum. I remember thinking that there must be some form of medication or a liver transplant that could save her.
- 15. On the day of her death we were called to the hospital urgently to say goodbye. However we never made it to Kings before mum passed away and so I never had the opportunity to say goodbye to her.
- 16. My mother's cause of death is recorded on her death certificate as multi-organ failure and submassive hepatitis necrosis arising from viral hepatitis (WITN0754002).
- 17. Prior to her showing symptoms arising from the Hepatitis C, my mother was a healthy woman with no chronic health conditions.

Section 3. Other Infections

18. My mother was infected with the Hepatitis C

Section 4. Consent

19. I do not believe that my mother was given blood without her consent; however I am unable to comment on the exact information that was given to her before the blood was administered. As I have already highlighted, it is likely that mum was not given adequate information about the risk of infection before blood was transfused into her. Neither my mother nor father could read or write so they would have had to receive advice verbally and would not have been able to do their own research into the risks.

Section 5. Impact

- 20. My mother's death changed our lives completely from what they could or should have been.
- 21. My older sister left school at 11 as is traditional in the traveller community; however I exercised a choice, given to me by my parents, to remain at school to complete my GCSEs. I did this because I wanted to make something more of my life rather than becoming a housewife like my older sister and the majority of women in the traveller community. I had aspirations when growing up of training to become a teacher and I hoped to obtain the necessary qualifications to do this. Everything changed when my mother passed away.
- 22. I immediately dropped out of Year 11 and never completed my GCSEs. As a result I have been unable to pursue a professional career and have been in the same job for the last five years that does not require any qualifications. My life has therefore changed dramatically as a result of my mother's death. After dropping out of school I had children shortly afterwards and worked as a cleaner. My current job as a "Weight Watchers" consultant is not what I wanted to do ultimately but it pays the bills. I made the commitment to stay at school so that

- I could prove to people that travellers can make something of themselves; however it wasn't meant to be once my mother passed away.
- 23. Things changed dramatically for us as a family as well as my father moved us from our home in the traveller's community to a permanent address next door to my present home and where my older sister still lives to this day. My father could not bear to live in the place he had lived with my mother when she was alive. We stopped being travellers in the usual sense because of my mother's death and are now settled people. I was quite angry about the decision to move us initially but we have adapted to life in a permanent residence. It has meant however that my children experienced a reduced connection with the traveller community. Things have changed for them because of my father's decision to move away, a decision only made because of my mother's death.
- 24. As my mother was only alive for a month during the period that she was aware of her infection, she did not live with Hepatitis C as such. I am not therefore sure whether my mother was given any treatment for the infection, and if she was, what the impact of that was.
- 25. It was so much to get my head around when my mother passed away. It was a lot to go through in a month. September 2000 can only be described as a weird month as we went from Mum feeling fine, to her feeling slightly unwell, to being called in as a family to say our goodbyes and ultimately to her death. I feel very sad that I never got to say goodbye to Mum. If it wasn't for Hepatitis C my mother would probably still be with us today. She would have been a fit woman during my teenage years had she not been given contaminated blood.
- 26. Losing my mother left a great gap in our family. Traveller girls are traditionally closer to their mothers than their fathers. Certain things

the girls will only do with their mothers, like going shopping. Had my mother been alive, I would have been able to do this and other "girly" things that a teenage girl would normally do with her Mum. My father did an excellent job of bringing up his three daughters but we did miss out as a consequence of our mother no longer being with us. My younger sister never really knew our mother as she was only three years old when Mum passed away.

- 27. I have been asked by the Inquiry team whether we as a family experienced any stigma due to my mother's infection. In our family and in the travelling community at large the word "hepatitis" is not really known so we didn't really experience any stigma. My father never talked about the cause of my mother's death and in any case, our friends never asked about it. Within the traveller community, the details and cause of a person's death are not as important as the fact that the person has died. For us, Hepatitis C was just something our Mum had died of.
- 28. We continue to keep the memory of our mother alive. My children know about their grandmother and what happened to her. However, Hepatitis C has robbed them of a Gran who I know would have been brilliant when they were growing up.

Section 6. Treatment/Care/Support

- 29. I am not aware of any obstacles faced by my mother in obtaining treatment.
- 30. I was not offered counselling as a result of my mother's death but would not have taken up the offer if it had been given. Travellers have very close knit families whom we rely on for support: I had my family to speak to about what had happened.

Section 7. Financial Assistance

31. I have been asked by the Inquiry team whether we were offered any financial

assistance as a family. This was never discussed with my mother or father as far as I am aware and we certainly did not receive any money from the government.

32. No amount of money would have brought my mum back but it may have helped my father bring up three daughters on his own.

Section 8. Other Issues

- 33. We would like some answers from this Inquiry. Could this disaster have been avoided? Would my mum still be here with us today? I think so. My mum was a fit and healthy woman before Hepatitis C took her life.
- 34. Even if my mother's infection was unavoidable, some form of warning from the government regarding the infection risk after the event would have alerted my mother to the need to get tested. This could have saved her life. As a family we were never made aware of the hepatitis risk or the need to get tested.
- 35. I feel like my mother should have her story told as she is a part of this disaster. These things don't really get spoken about in the traveller community: no one has asked about the circumstances of my mum's death. These things are not asked and are kept private within the family. However my sisters and I are happy to share our experiences with this inquiry.

Statement of Truth

	that the facts sta	ted in this witness
Signed	GRO-C	
Dated _2	12.05.19	