Infected
Blood
Inquiry

Witness Name: Christine Thomas
Statement No.: WITN0464001
Dated: 3/4/19

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHRISTINE THOMAS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 January 2019.

I, CHRISTINE THOMAS, will say as follows: -

Section 1. Introduction

1. My name is Christine Thomas. My date of birth GRO-C 1979 and address are known to the Inquiry. I am a mother, a wife and I currently work as an engineer for the NHS. I intend to speak about my mum's Hepatitis C antibody positive ("the antibody") diagnosis. In particular, the nature of the antibody and how the antibody diagnosis affected the family and I. I will not be making a commentary on any treatment, as my mum did not receive any.

2. I am not legally represented and I do not require anonymity due to the fact that my surname is relatively common and I do not believe that people will know who I am from this statement.

3. I have recalled some of my experience by anchoring them to memorable occasions in my life.

4. Please read my statement in conjunction with Genevieve Jones', to gain a more informed overview of the family experience.

Section 2. How Affected

5. During my birth in 1979, I was delivered much faster resulting in blood loss, which in turn required my mum to receive a plasma drip. This was either at Woking Community Hospital, where I was born, or the Royal Berkshire Hospital where she was transferred.

6. My first memory of my mum's health would have been when I was around the age of 10, or possibly younger. My mum was an avid blood donor and I can recall attending the blood bank with her a number of times. Around this time, I remember my mum being told that she could no longer give blood. I do not believe that I was aware as to the reasons why or the circumstances concerning this, at this time.

7. My mum was informed of the antibody diagnosis in either 1989 or 1990, ten years after receiving the plasma. I do not believe I was directly told about my mum's diagnosis. Rather I remember the situation being discussed a lot growing up and I understood the general gist of what was the problem. Around the age of 12, I recollect visiting the Royal Free Hospital in London for an appointment for my mum. I have the memory of sitting in the corridor with my dad. I don't remember waiting for too long however I do recall my mum telling me that she had to have a long needle.

8. I vaguely remember that the results came back stating that she has the antibody as opposed to the virus. This was a few weeks following

the hospital appointment. I recall there being a lot of confusion and discussions as to how and why my mum has the antibody.

9. I would like to make it clear at this point in my statement that neither my mother nor I understand what an antibody is or what it means for my mum in the future. It was never explained to her and I am unaware of how an antibody affects a persons' health, if at all.

10. Over the years there have been many conversations relating to how and why my mum had developed the antibody. The family first thought that the antibody was caught from a Hepatitis A vaccination that my mum was given when she was younger. My granddad contracted Hepatitis A whilst they were living in East Africa. However, a medical professional, who was one of my mum's consultants, later dismissed this theory.

11. Early on, when the medical professionals were still trying to understand how my mum had contracted the antibody, the consultant asked my mum if she had received any blood transfusions. My mum told them that she had received a plasma drip, to which she was told that she would not have contracted the antibody from plasma, as it is a blood product. It was as though the consultant scrapped the idea that the plasma may have caused my mum to have the antibody and moved on asking further questions.

12. To the best of my knowledge I am aware that my mum was not provided with advice regarding the risk of being exposed to the antibody or any kind of infection prior to receiving the plasma drip.

13. My mum was not provided with any information regarding what an antibody is or what it means. I feel very disappointed because of this. It feels as though because my mum doesn't have an active virus, she doesn't need any information regarding what she does have.

14. I am of the opinion that my mum doesn't have a specialist HCV nurse and isn't under a specialised unit as I am for my health condition. The problem with this is that if something was wrong, she has no direct contact to someone or a place to call or go to for help. Although neither her nor I would know what to look for if something was wrong.

15. Due to my mum being made aware of the antibody in the form of a letter from the Blood Transfusion Service, she was advised to speak to her GP and was then referred. At none of these stages was the antibody diagnosis explained to her. Looking back it seems as though they didn't feel that it was important to explain it to my mum. My mum has not been provided with any information regarding the condition of her liver or whether having the antibody weakens the liver in any way. No information was given as to whether there is precautions that need to be taken.

16. I do not believe that adequate information has been provided to my mum about what an antibody is or what it means and it should have been. I am aware that people have died and that my mum is at the lower end of the scale, however it does not take long to create a quick informative pamphlet. There appears to be no support mechanism. What about those people who are still alive?

17. I believe that the results of the tests could have been communicated differently.

18. No information was provided in regards to the risk of infecting others. There was no explanation at all of any potential risks.

Section 3. Other Infections

19. I do not believe that my mum has contracted any infection other than the antibody.

Section 4. Consent

20. I am of the opinion that my mum would not have been tested or treated without her consent in regards to giving blood, because you sign a form when you give blood approving that your blood will be tested. She would have consented to this with the strongest belief that her blood would have been accepted and donated as opposed to being told that she was antibody positive.

21. On reflection, given the circumstances of my birth and the immediacy after I was born, I am unsure as to whether my mum would have signed a consent form to receive blood in case of an emergency. It is an unknown quantity. I am unaware if it was an emergency situation or if they just needed to top up her plasma levels.

22. I believe that my mum was aware that she was being given plasma.

23. I am of the view that my mum was most likely not treated or tested for the purpose of research. I do hope not. I hope that the antibody positive result was spotted and then relayed.

Section 5. Impact

24. I have had no physical impact due to the fact that I am an affected person. However, the mental impact has been significant over the years.

25. Growing up over the years, it didn't affect me too much. I was young when my mum first received her diagnosis and when I was a teenager I enjoyed going to London for a day out. Most likely because I didn't appreciate the gravity of the appointment. I remember thinking and questioning why my mum had to have special tests and why they couldn't be done in Wales at our local hospital.

26. As I came into my late teens, I became more aware as to what was going on. My career has been within the engineering world and so I became inquisitive and began researching, digging and questioning a lot more.

27. Emotions run deep in the family in regards to my mum's diagnosis. There is more worry now than there ever was before because my mum was diagnosed so long ago, back in 1989 and we are all still none the wiser as to what the diagnosis means.

28. My mum doesn't like to trouble people with any problems she may have. I worry that she wouldn't ask me to go with her to any important appointments because she wouldn't want to impose as I have my own life and family.

29. When I think back, she used to zone out and became quiet. When my dad would ask what was wrong, she would reply saying nothing. We could all tell she was thinking about something that was maybe worrying her but she wouldn't tell us. My dad used to probe her further and she would just burst into tears. We would never know what it was that she'd think about. On other occasions, she just internalises everything and then explodes over something silly.

30. I think my mum finds it hard to confide in people because she doesn't want to worry us. She would have confided in my dad, as they were a unit. Even if there were a small detail or a piece of paper once received, he would have remembered it.

31. Even though we may still be able to gain information as to what my mum's current health is and what an antibody is, I can go with her to her appointment to comfort her, but inevitably she will go home alone. She won't be able to have a hug from my dad to comfort her before she goes to sleep at night.

32. My mum receiving the antibody diagnosis was very difficult for her. More so, because she was very passionate about giving blood and was given badges to commemorate how many units of blood she had donated. After finding out she could no longer give blood, there was an element of concern. She wouldn't have been worried for her, but more so for the people who had received her blood in the years after she had received the plasma drip.

33. I do not believe that my mum has suffered any further medical complications or conditions as a result of the antibody. She has GRO-A GRO-A which a part of me wonders whether it may be caused by stress or linked to anxiety about the antibody. I also wonder if the stress that my dad was diagnosed with was caused by his worry for my mum too.

34. My mum wasn't given any treatment; she was tested and is monitored. It begs the question, however, of why does she need on going monitoring if there is no illness? It is a resource of the NHS and so why waste it if there is no need?

35. My mum has had no difficulties in obtaining tests or being monitored. I do believe that further testing should have been made available. I am aware that she has never had a scan or ultrasound on her liver, just blood tests. If having the antibody means that she would have had the virus, what damage was done whilst she had the virus?

36. In regards to dental treatment, my mum wouldn't have been treated any differently as it is not an active virus. My belief is that she may not have to declare it.

37. I have anxiety and worry an awful lot about my mum. I have frustrations that my mum and my family do not have access to information. My mum may not want the information, but information for the family could have at the very least been provided.

38. I feel concerned about my mum, and it is always playing on my mind. It has created an added anxiety on top of everyday life. For example, on odd days when my mum is feeling rough, tired and lethargic. Is that because she is tired from work or is it because of the antibody? Neither my mum nor I know what the side effects or symptoms are and therefore I are unaware as to whether this is something to worry about.

39. It is a fear of mine that my mum may feel as though she has to deal with all of this on her own. If my mum would have been provided with information at the time of diagnosis, her and my dad, who is sadly no longer with us, could have dealt with it together.

40. I am aware that people associate Hepatitis C with HIV, AIDS and drugs. I personally, never saw that side of things. It was always openly discussed in my family.

41. My mum has worked in a supermarket since it opened. She has never been one to want to progress. Recently she has been applying for a new job. We are unsure as to whether she would need to disclose her antibody positive diagnosis.

Section 6. Treatment/Care/Support

42. My mum was never offered counselling or any psychological support. I do believe that she would have benefitted from this. She doesn't know what it is or what it means to be counselled and she can't evaluate it.

43. The Inquiry has now made me aware of the work that the British Red Cross (BRC) are doing to help with counselling for people who have been infected and affected by infected blood. I have been provided with a card with the BRC's counselling details and I will consider whether I will access this service.

44. There were no local groups she could go to, to meet up with people alike. All things like this were always in London and never local to us.

Section 7. Financial Assistance

45. On behalf of my mum, I contacted the Skipton Fund. I spent a long time on the phone explaining the circumstances. In response I was told that my mum must have spontaneously healed and therefore was not allowed any financial assistance. We were declined at the point of entry and dismissed by the Skipton Fund.

46. At that point the Skipton Fund could have signposted or directed me to the Hepatitis C Trust or other organisation to help me understand why my mum was not eligible.

47. This makes me feel frustrated and question whether this is fair. I understand that a line has to be drawn somewhere however to be shut down the way that I was, is quite cold. When I saw an advert in the media, it seemed like a caring organisation, however they dealt with me in a cold and callous manner.

Section 8. Other Issues

48. I am seeking some kind of reassurance. I want closure for my mum, for somebody to say sorry that we didn't warn you of the risks and that we didn't tell you your problems. We made you guess.

49. Cash is nice to have but it is not the only thing that is needed. I want recognition of responsibility and someone to confess and say that they got it wrong.

50. I am not looking for anybody to blame because the decisions that are made are made by a group of people at the top. Those accountable

should be the ones to stand up and apologise, and for it not to be trickled down to the newest CEO at a local health board to apologise on their behalf. It would not have been their fault as it would not have been their decision.

51. Sorry is a hard word to say. I want those responsible to admit that they don't know everything. This would put fear in people but people need to be made aware. It isn't right to treat the public like they know nothing; we need to be treated with respect. In this day and age, you can't do that; you can't make assumptions.

52. There needs to be a level of respect for patients. I work for the NHS and patient care does not come first at the top. I believe that the NHS needs to look at value and long-term solutions, not fast fixes for a cheaper solution. This however, has not been the cheaper solution because of how much this has cost them in the long term. I can imagine that at the time that this was happening, people knew that it was wrong and agreed not to say anything.

53. I would like an apology issued from whomever made the call and an admittance that this was all money-driven.

Statement of Truth

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

Signed GRO-C

Dated 3/4/19