

Witness Name: Helen Ludford-Thomas

Statement No.: WITN5514001

Exhibits: None

Dated: May 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF HELEN LUDFORD-THOMAS

I, Helen Ludford-Thomas, will say as follows:-

Section 1: Introduction

1. My name is Helen Ludford-Thomas and my address is GRO-C
GRO-C and my date of birth is GRO-C 1974.
2. I am married and have three children. This is my second marriage and I have two daughters from my first marriage and a son from this marriage. My husband and I are both musicians and teachers. My two daughters are at university and our son is aged 11 and still at school.
3. I provide this statement in relation to my father, David Robinson who was born on GRO-C 1944 and died on 22 April 2010. My mother has also provided a witness statement at WITN3046001.

Section 2: How Affected

4. My father was diagnosed with mild to moderate Haemophilia A when he was 4 years old and following that diagnosis he was under the care of The Royal Hallamshire Hospital, Sheffield. I believe he may have been given some blood products during his childhood, but I am not aware of the details. I know that my father attended a dental appointment in 1978 for a tooth extraction and he was given a 50 mil vial of Factor VIII to prevent post-extraction bleeding.
5. My mother informed me that my father had received a couple of letters in 1995 asking him to attend the Haemophilia Centre. The letters did not say why and were quite vague and I think my father did not really think too much of it because he was no better or worse than he had ever been. Later in 1995 my father then had a health scare when a mole he had would not stop bleeding and his GP sent him to the Haemophilia Centre. There had been no ongoing contact with the Haemophilia Centre prior to that.
6. When my father attended the Haemophilia Centre he was informed that he had Hepatitis C. I believe it was Dr Makris who was his consultant at that time. This diagnosis was a bolt out of the blue.
7. I have spoken to my mother and asked if they were informed of any risks that might have been involved in having the blood products and she confirmed that they were not.
8. My mother has also said that they were not provided with any information at the time of his diagnosis and that was consistent all the way through my father's illness. My parents were not offered any advice or assistance when he was diagnosed, they were just informed that there was no cure and how to avoid transmission and that he had been infected from a batch of Factor VIII that he had been given to him 1978. This had been when my father had attended a dental appointment at The Royal Hallamshire Hospital Dental Department for an

extraction. That was all the information they were given. My father had therefore been infected with Hepatitis C since 1978 and had not known about it until 1995.

9. I do feel that my parents should have been informed sooner, not least because life might have been very different had he known what he had. My father could have looked after his health in very specific ways which he did not do due to not knowing. If you are aware you have Hepatitis C then you will do very specific things, for example you would not drink alcohol and of course my father had not avoided alcohol. It would have been easier as a family to manage a condition that was a known entity, but in order to do that we would have needed to know that he had been infected.

Section 3: Other Infections

10. I am not aware that my father had any other infections as a result of receiving blood products.

Section 4: Consent

11. I do not know whether my father was ever treated or tested for the purposes of research.

Section 5: Impact

12. Haemophilia is something that my family have lived with my entire life. My son has it now and so we continue to live with it. My father was given the contaminated blood products in 1978 when I was four years old, but he was not diagnosed with hepatitis until 1995, by which point I was away at music college. Looking back now, when you know he had Hepatitis C, I can see that it affected everything because he was always ill.

13. My father was always afflicted and it was a stressful house to grow up in, there was just a lot of tension in the house. It was a stressful place to live and looking back and not knowing why my father was ill and what all his symptoms were must have been an awful time for my parents. My parents are quite tempestuous anyway so I do not think that helped. I am one of those people who just gets on with things, but as an adolescent, I hardly ate for years. I was a tiny child. I weighed six stone when I got married in 1996 and I am five foot six.
14. As a child and teenager I did not concern myself with my middle-aged parent's health concerns. I was not really paying much attention to why my father might feel like this or that. However, ultimately my father's health did have a big impact upon my parents' relationship and upon the whole house.
15. I know that my father tried to lead a normal life, even when he felt ill. He became increasingly compromised over that period of time before his diagnosis. As with any illness, if you have many symptoms and you do not know why, that is almost worse than knowing what you have. At least if you know you have a label for it and then you can make a plan and then you can behave in a certain way. If you do not know, you are afflicted in isolation with no explanation and it is one of the most frightening things.
16. My father suffered with bloating, itchy skin, nausea and general tiredness, however, all of those things lead to other emotional things such as irritability and irrational behaviour. If you are afflicted endlessly, as my father was, then you are not going to be your best self. Equally, my father was not a complainer and so quite often I would not know when he was ill or exactly what was wrong with him. He would never say "*oh actually, this really hurts*", or "*I'm feeling like this today*". That was not his manner and he never complained, but never went to the doctor either.
17. The decline in my father's health had been slow over the years. It was not the case that he was well one day and ill the next. Throughout my childhood my

father was just my father. I believed that he looked the way most middle-aged men looked. However, I went away at 18 years old to music college and then came back home, and that was when he was getting to be particularly ill and he looked terrible. He looked jaundiced, he looked gaunt and he was frail. He was not very old, looking back, he was not much older than I am now and that was a real shock to see him like that.

18. When my father was diagnosed with Hepatitis C he was sent for lots of testing to see how badly damaged his liver was and my parents were informed immediately that he needed to have a liver transplant.
19. Shortly after the diagnosis of Hepatitis C my father became really ill. He was vomiting blood and had a burst vein in his oesophagus, a massive haemorrhage. We nearly lost him that night and my father was in hospital for a number of weeks afterwards. We had gone from not knowing he was ill to almost losing him and it was a horrible time.
20. My father returned home from hospital and after around two weeks my father had a further haemorrhage. This was not as bad as the first one and the hospital managed to stabilise him. I believe this was when my mother was then taught how to give my father intravenous infusions at home every other day of Factor VIII and Factor IX to stop any further bleeds. My mother did that indefinitely.
21. I remember on my wedding day that my mother was having a huge panic because they could not get the right product for my father and we were not at home. It was very traumatic, but my mother managed it. She fixed him and he did manage to walk me down the aisle. I remember thinking through the whole day *"is he going to keel over any moment?"*.
22. I am not aware that my father received any treatments for Hepatitis C other than his liver transplant in September 1996. I was not living with my parents at the time, but I saw a lot of them. There was a kind of sense of euphoria because my

father had received this new liver and the operation had been a success and they were very happy. The liver was accepted by my father's body and he was obviously in better shape than he had been leading up to the transplant.

23. My father was fine initially after the transplant, but he then started to deteriorate and my mother raised concerns with the hospital. It subsequently transpired that the hospital had given my father a liver with Hepatitis B. My father was immunosuppressed, so then that started to go wrong all over again. The worst part about that was the fact that they did not know what was wrong and my father was accused by the doctors of drinking alcohol after having a transplant when he had not been. My father had done everything that they had asked. He wanted to be with his family and this new liver was a new lease of life and he was not going to jeopardise it. The fact that he continued deteriorating was all the more traumatic, because it was, not that any of this is deserved, but it was particularly not deserved having done everything he was meant to do and his condition still got worse.
24. I understand that my father was clinically prepared for a second transplant but due to my father developing cancerous cells in his oesophageal varices he was not well enough for a second transplant and was then taken off the transplant list. My father passed away on 22 April 2010.
25. I do not believe that my father experienced any obstacles in obtaining treatment for his Hepatitis C. Once he had been diagnosed my father did everything he was told to do and he was quite strict about it. Whatever treatment my father was offered he would have taken it.
26. My father, who was an accountant, had continued to work as much as he could, but not as much as he would have been able to had he not had Hepatitis C. He did go back to work after his transplant but a little while later he had to give up work altogether. My mother, who is a nurse, looked after him. My mother's career did not progress, she did not apply for any promotions, or look for anything new,

she just held the same position. That was to keep earning the money, to keep paying the bills and to keep a roof over our heads. There was no question of them having a wonderful time in their 40s and 50s when they should have been at their peak of their earning powers and their professions. All of the things they would have worked towards, that just did not happen for them, they were just holding it together really.

27. My parents' social lives changed completely. Back in the day in Grimsby and Cleethorpes where they lived, it was very much a pub culture. That was where they met their friends, they went out for dinner, they drank, and of course my father was not able to do any of that anymore and so he actively avoided it and that was really sad. They could not socialise with all the people he had grown up with as my parents had always lived there. They were not able to go on holidays with other people, they did not go out and meet up with them in the same way they had done previously. My father was an invalid and that stopped him from doing all kinds of things, it was really sad, because he had been such a sociable person.
28. At the time we just got on with things. Music was my thing, that is what I did, that is what I still do, and it made me very focused on that and pretty much nothing else. I do not think any of the family found it easy over the years. Our home was a stressful environment. My mother looked after my father and I just did not eat anything. I literally just went into my own little world and played the piano for hours, that was my coping strategy. I have been the same for years. I think probably until I had my own children. I am a bit more well-rounded these days and I do a bit more than play the piano and I do definitely eat food, but for a long time it was problematic. I would not have said there was anything wrong with me, but if I was my own mother now I would be like "*oh my god, this isn't normal behaviour*", it was just the way I did things to cope with the stress.
29. I am the sort of person to say "*well, that happened and we got on with it and we have a nice life and it's all fine*", even though that is not the full story at all. It was

a really difficult time and it had a massive impact, but you have to get on with your life and do things day by day, you cannot sit feeling sorry for yourself.

30. We did go on holidays when I was much younger. By the time I was a teenager we went away less and less. My parents were quite stressful to be around and so I would much rather be off on a choir trip or something that took me away from it. My parents were brilliant and they supported everything that I did and they were very kind and very proud, and equally it gave me a chance to do something separate from their slightly charged environment.
31. I am now really independent and when I did leave for music college when I was 18 I never moved back home. I bought a house and transferred all my things there and I have been independent ever since. I have my own lovely house and lovely family and my children, who have a much easier environment to live in which has been quite a big mission of mine.
32. The financial outcome of my father's condition had a huge impact on both of my parents. My father could not work to his full capacity and neither could my mother and money was always an issue. We were never poor, but it was always tense, and again these are things which I have always sought to avoid. Considering I picked to go into music as a career I have managed somehow to have a stable household and everyone has what they need. It always was stressful growing up, and my parents were always checking if they could afford this or afford that, my music lessons for example. Looking back now I had a very privileged middle-class upbringing, but it did come at a cost. My parents did work as hard as they could.
33. You would think that an accountant and a nurse were really good solid, stable jobs, but not if your health is not stable, and not if your parents are not stable with each other. In addition, there was also a psychological concept of the unnamed dread of not knowing what was wrong with my father, that was much worse than knowing what we were dealing with.

34. With my first two pregnancies I was tested to make sure I was having girls and then the third time round I was not tested. We had a boy and he does have haemophilia. My husband and I knew that haemophilia is recessive in the sense that if I was passing on mild to moderate my son was not going to be severe. He was always going to be born with haemophilia, and having seen it in my father, although it did not end well, his actual haemophilia itself was okay on a day to day basis. It does not require particularly careful handling and we were aware of it, but like any inherited thing in families it did not seem onerous.
35. My mother coped with all of this on her own. She did not have anyone to help her. My mother is tough and thank goodness she is a nurse and was able to look after my father, but I think even if she had not been a nurse, she would have just got on with it, that is just how she deals with things. She has done that her whole life.

Section 6: Treatment/Care/Support

36. My parents were never offered any advice or counselling. We live in a slightly different world now where people would expect that. It was not an expectation back then and it certainly was not available. My father just had routine outpatient appointments. The fact that he was dying seemed to be just one of those things. There was no kind of compassionate care, nothing at all.

Section 7: Financial Assistance

37. I am aware that my parents were given three payments of £20,000 to mitigate against loss of earnings but I do not know any further information.

Section 8: Other Issues

38. I think moving forward families really need to be looked after. It cannot be the case that *"this has happened to you and this what we are going to do about it"*.

There needs to be more understanding about the situation that families find themselves in as this has been catastrophic.

39. I have been told by my son's haemophilia team that the blood products that he may get, if he ever needed any, are now synthetic, so this is a great thing.
40. I do not wish my evidence to be anonymous.
41. I would be willing to provide oral evidence should I be required to do so.

Statement of Truth

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

GRO-C

Signed

Helen Ludford-Thomas

Dated..... 14/1/22