

MIKE

Witness Name: Sally Wilde

Statement No.: WITN3759001

Exhibits: **WITN3759002**

Dated: 11-12-2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SALLY WILDE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 05 September 2019.

I, Sally Wilde, will say as follows: -

Section 1. Introduction

1. My name is Sally Wilde. My date of birth is GRO-C 1961 and my address is known to the Inquiry. I work at Forest Green Motors which is a business that my husband, Philip Wilde ("Phil") and I own.
2. I can confirm that I am not legally represented. The investigator from the inquiry has explained what the anonymity process is and I do not require it.
3. My statement should be read in conjunction with Phil's statement (WITN3702001).

4. I intend to speak about my mum Lily Emily Davis and her Hepatitis C infection ("HCV"), which she contracted during her treatment for leukaemia. In particular, I will speak about how mum was not told of her diagnosis, how the lack of information affected her and us, the impact it had when she passed away and it was discovered, and the lasting effect it has had on us following her death.

Section 2. How Affected

5. While my mum was poorly a lot of her life, she started becoming much worse after the death of her husband, my dad, around Christmas time in 1986. While we were worried about her, we thought it was just her grief due to the loss of dad, but she began to really deteriorate 6 months after he died, she was really struggling. She was continually fatigued, and had lost her appetite. She lost weight and was gaunt in appearance.
6. After visiting the Doctor and having several tests, she was diagnosed with leukaemia. During this time her Doctor providing treatment was Dr Mackey. Her leukaemia required a lot of going back and forth to the Wexham Park Hospital in Slough and she was also seen at the John Radcliff.
7. Due to mum's poor general health and her cancer, her immune system was getting worse, and she was offered a blood transfusion. Between 1987 until the time she died mum received several blood transfusions as part of the treatment of her leukaemia.
8. Mum consented to all treatments offered to her for her leukaemia. At that time, she accepted all possible treatments offered by the John Radcliff for, as she would say; "leukaemia is a very difficult thing".
9. As far I am aware, mum was never not given any information or advice about the risks associated with blood transfusions. I was certainly never

present when such information was provided and I am sure she would have mentioned something to me if it was discussed.

10. Although mum's health was never that great, her problems were more bronchial related and I am almost certain that she had never had a blood transfusion in the past. She certainly did not use intravenous drugs, had no tattoos and was happily married to my father up until his death.
11. During this time, we would visit Wexham Park weekly, then fortnightly, then monthly. Blood tests were taken to monitor the cancer.
12. As I was very upset having had lost my dad, and with mum ill, I never asked any questions about what blood tests were being done, although I know that blood was taken every visit. Surely with a blood related cancer they would be checking for any abnormalities?
13. Mum continued to struggle through the treatments although it was clear that she was ill. She remained fatigued more so than for her age and her loss of appetite persisted. She complained of joint aches, although we were never sure if these were the result of her working on a farm during the war. I recall that she had terrible difficulty in sleeping, a very disruptive sleep pattern. She also often had episodes of "brain fog" – you would be in conversation with her and she would look straight through you, her mind elsewhere. However, her death still came as a huge shock when she died on the GRO-C 1994. There was just no reason to expect it to be so sudden.
14. On the day she passed away Phil received a telephone call as she had become unconscious, so he and I immediately went to where she was staying at the time – she had been housing sitting for a friend – mainly watering their plants.
15. She was on the bathroom floor when we arrived, so having a first aid certificate and a father who was a paramedic, Phil went through the basics, checking for a pulse and her breath.

16. He then tried to resuscitate her by giving her CPR, the kiss of life, while we called an ambulance. He continued to try and revive her for a while but she was gone. I know, she didn't want to be a burden, and she didn't want to be a vegetable. She was always so independent, I struggled with that and felt terrible that I never got to say goodbye.
17. The ambulance arrived and confirmed she was dead and she was transported to Wexham Park Hospital. Once we were in the relatives' room they said they at first thought she had died of a heart attack, there was no mention of any infection.
18. During the years of her illness I had made myself available to assist her. My work had to be flexible because when she needed treatment she needed to be taken and accompanied, and there was no one else involved other than me – and I couldn't let her go on her own. I couldn't afford to drive all that way to take her to her various appointments, my father-in-law helped arrange transport for us both.
19. There were many, many appointments with doctors and nurses and mum and I were never told that she had contracted HCV. Mum was a very proud woman, so in some way perhaps that she did not find out could have been a blessing in disguise as I don't know how she would have reacted. The infection is one many associate with drug use and prostitution so she would have been mortified.
20. We do not know how her treatment could have been affected or influenced if she had been properly informed about her HCV infection. Was her cancer treatment adversely affected? We will likely never know.
21. It was with Dr Sparrow two weeks after mum's passing that I found out that mum had had Hepatitis C. As far as I remember, he said that because of the treatment mum had received, there was something that could have infected her.

22. As far as I can recall, it was not explained to me that the HCV infection had been or could have been transmitted to mum through her blood transfusions.

Section 3. Other Infections

23. We do not know if mum was infected with other viruses that could be transmitted via blood transfusion such as HIV, and it is possible that she was not tested for these, or possible that she was tested for these without her knowledge or consent. "The Doctors never mentioned HIV, so I just don't know". Similarly, there was never any mention of liver disease or as far as I am aware, any test carried out for this. I don't believe she contracted any other illnesses that may have been related to or exacerbated by the virus.

Section 4. Consent

24. As far as I am aware Mum was not told, nor consented to being tested for HCV. As I have mentioned, she had numerous blood tests in connection with her specific type of cancer and I would have expected that any irregularities in her blood would have been scrutinised. This is why I find it so difficult to understand why nothing was ever said to us about the infection.

Section 5. Impact

25. While mum had been ill, her death was very much unexpected. We were told that because she had leukaemia a post-mortem was needed. The post-mortem was completed in Reading.

26. After all the family met with the Doctor, Phil and I were asked to stay behind, and that's when we were told that mum had tuberculosis ("TB").

27. Her death certificate records that the cause of her death was (1a) Pulmonary tuberculosis, and (1b) chronic lymphocytic leukaemia. (See Exhibit WITN3759002)
28. We were told the coffin had to be sealed, and I remember we looked at each other in horror. We were thinking; "What the hell?!". We assumed that it was because of the TB that the coffin was sealed, but we weren't actually told that by the Doctor. I had never heard of a coffin being sealed for that reason before.
29. We never knew that mum had TB, so it was a shock to us. She never appeared to have any of the symptoms of TB. Obviously, we did not expect her coffin to be sealed, so none of it really made any sense to us. We were all still in a state of shock at her unexpected passing and didn't really press for further explanation.
30. The Undertaker then confirmed to us because of the post-mortem it must be sealed, and that was that. Nothing else was said except that it meant she had to be cremated and could not be buried. Although I do not think she would have minded that, any choice in the matter was removed.
31. Phil and I always had the feeling that there is something that they are not telling us, there is something that they are hiding from us.
32. We were both always suspicious about the TB diagnosis too, as she often had had chest X-Rays, so surely if she had had TB they would have picked that up then. TB is also an airborne infection so why the need to seal the coffin?
33. My sister Brenda was away when mum died, she came back that day and she really wanted to see mum's body, but she was not able to. I know that it caused her a great deal of stress and regret as she felt she should have been there to see her.
34. It was the meeting with Dr Sparrow two weeks after mum's death when we learnt of her HCV, that we were also told as Phil had tried to

resuscitate her, there was a risk he could have been infected too and that precautions should be taken. We were stunned. It was a double blow. Not only had mum unknowingly lived with this infection, now my husband could have contracted it also. Of course, Phil had no idea when he tried to revive her as no one had ever mentioned it to us.

35. I wish that I had known of the infection while she was having treatment and while she was suffering, I think we would have been better able to deal emotionally with everything. "And now to think...all that time when she was not only suffering from cancer and the associated treatments, but also had Hepatitis C". What impact did that have on her cancer medication? Did it contribute to her sudden death? We are left with many questions and the biggest one at the time was Is Phil's life at risk?

36. Phil had to have an X-Ray as well as blood tests over the course of a year and it was an awful. It was a year of wondering and worrying whether he had been infected too. We didn't tell anyone. It was our own decision to not tell anybody, and during that time it caused us a lot of anxiety in our personal lives. But this is not the sort of thing that you want to broadcast to the world.

37. Our social lives were also heavily impacted. We wouldn't go out and socialise because it was too difficult. We weren't comfortable and were scared Phil could somehow infect someone. We didn't really get much information on the HCV and its possible consequences and on how to manage it

38. Family stopped visiting which we put down to our house bringing back sad memories for them as mum had lived there with us for many years. We felt very isolated.

39. Phil had to take special precautions in the home too, having separate tableware, towels and toothbrush. We had to keep everything separate and this causes angst in a loving household.

40. If he got a cut at work, no one was allowed to touch or go near him. He had to carry a medical card too.
41. Phil's and my intimate relationship was affected as there was a risk of transmission. Of course, by the time we were advised of this we had already unknowingly exposed ourselves to multiple risks of transmission since we hadn't known of mum's HCV during her lifetime and not until two weeks after her death.
42. At the time we found out about mum's HCV and the risk of infection, Phil was working in a warehouse and held a first aid certificate. He didn't have any other choice but to tell personnel there about the risk, and because he was in a physical job where he could have got cut, he didn't have any other choice. His certificate was suspended for a year.
43. I know his salary at the time included a supplement for the first aid certificate and that was reduced, but it wasn't a lot of money.
44. I have suffered from anxiety and depression for some time. You wouldn't believe the amount of treatment I've had. Much of it is related to the provision of care for my mother over the years. Although there are other family members the burden fell mainly on me and then Phil when we became a couple.
45. Some of the drugs have now caused problems with my nervous system that can't be reversed. I was on the drugs when mum died, and with the shock of losing her then, and then not knowing about the tests and the hepatitis, allied to the worry about Phil it all added up and it was horrible.
46. My mental health also suffered significantly more due to the additional stress and strain caused by what happened after mum's passing.
47. They should have told us about the infection. They must have known of its existence. They should have been more forthcoming about what it was - even if they were not exactly sure - and what it meant, especially because of my anxiety issues.

48. If we had known about the infection we could have taken precautions during mum's lifetime, and Phil wouldn't have been exposed to the risk of infection and the following trauma when mum passed away.

49. We suspect we also would not have had the shock of having the coffin unexpectedly sealed when mum passed away. Things would have been very different.

Section 6. Treatment/Care/Support

50. As far as I am aware mum did not receive any treatment for her HCV.

51. I had bereavement counselling for months and months following mum's death. This was offered to me by my GP, Dr Collier, when she took over from Dr Sparrow. Dr Collier was an excellent Doctor.

52. I was never offered counselling specifically related to the HCV, nor was Phil.

53. While we knew Phil had to be tested for HCV we were never really told what it was exactly or what it meant. We knew it was HCV but he had to research himself to find out that there was a 9 to 12 months incubation period and that was why he had to have continued blood tests.

54. The last test was about 6 months after mum's passing, and Phil was never actually given the result. The only reason he found out that he was all clear is when he went to the GP on an unrelated matter, and they happened to mention "oh I see you've been tested for Hepatitis C.... and that's all clear".

55. Even though I was the one that had looked after mum, as far as I knew I was not tested for HCV. When looking at my medical files now, it looks as if I was tested for HCV, but I don't believe I was told that at the time and I do not recall ever consenting to the test or being told the results.

Section 7. Financial Assistance

56. Mum did not receive any financial support or assistance in relation to her HCV infection. No mention was ever made of such support by any medical professional.

57. Phil and I have not received any financial support or assistance in relation to mum's HCV infection, nor in relation to the impact on us.

Section 8. Other Issues

58. Phil and I feel that the medical profession went to great lengths to bury information about mum's HCV. They would have been aware that she had received a blood transfusion in the past so surely would check her blood thoroughly, especially with her leukaemia diagnosis. They should have been more open with us and they should have given us the information we needed. Even after we were told about mum, it was two further weeks before the possible risk to Phil was mentioned. Why wait those two weeks

59. As I said, in some ways it could be a blessing in disguise that mum didn't find out about her HCV, that she went without knowing. I feel just so sorry for those finding out now as I know mum would have felt just awful.

60. I still struggle with the fact that, even after all the years, mum and I were at the hospital and the surgery so often, yet nobody was in contact after she died. All of a sudden, you're finished, and that's that, I found that very hard. I still depend on them but it has diminished my trust in the NHS and I don't think I would be so quick to accept a diagnosis without question in the future.

61. Things would have been much easier if we had been given a simple explanation of what Hepatitis C actually was.

Statement of Truth

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

Signed

GRO-C

Dated

11-12-2019