Witness Name: Ashley Walker
Statement No.: WITN2035001
Dated: 19 December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ASHLEY WALKER

Section 1. Introduction

1. My name is Ashley Walker. My date of birth is GRO-C 1989 and my address is known to the Inquiry.

2. I live in London and work as an actor. I am writing this statement about my mum, Karen Fox, who was infected with Hepatitis C ("HCV") as a result of a blood transfusion in 1989.

Section 2. How Affected

3. My mother was infected by a blood transfusion that she received in hospital after giving birth to me in GRO-C 1989. Please see the statement of my mother, Karen Fox, for full details of how she became infected **(WITN2012001)**.

4. I understand that my mother was diagnosed with HCV about 2-3 years after I was born. She had recently received a kidney transplant from her father and tested positive for HCV, so the doctors initially thought her father had given her HCV through the transplant. They realised when he tested negative that she must have gotten it from her blood transfusion.

5. My mum was told of her HCV infection by a doctor in passing, which I think really affected her for years. She was embarrassed to be told so publicly, and wasn't given any information at the time about the prognosis of the infection or what next steps she should take, so she felt powerless to cope with her diagnosis.

6. My mum was very anxious about passing on HCV to me, likely because she was not given proper information about the risks of transmission. As a result she took me to the doctor every 6 to 12 months to have an HCV test, and refused to let me touch anything she had touched in the house for fear I might catch it from her.

Section 3. Other Infections

7. My mother was only infected with HCV.

Section 4. Consent

8. I believe that many times decisions were made to treat or not to treat my mum for various conditions without giving her adequate information to make an informed decision. Several times she went into surgery without knowing what procedure was going to be done. She always refused to have a liver biopsy due to its invasive nature and the risk to her kidney, but was eventually pressured into having one and then the biopsy caused her kidney transplant to fail.

9. I feel that my mum is consistently ignored or not taken seriously by doctors. She has a multitude of complications arising out of her kidney failure and the HCV, and in many instances they have not been adequately dealt with. She has often not been given information about how or why something has happened to her, or she has been made to feel that it was her fault. For example, she has been made to feel that if she was eating better she wouldn't have diabetes, when it was later discovered that a medication she was taking had caused her diabetes.

Section 5. Impact

10. The physical symptoms of HCV that my mum has are sometimes hard to distinguish from the symptoms of her kidney failure. She developed kidney failure at the same time that she contracted HCV, and has had four kidney transplants since then. But from an early age I remember her being tired, having serious nose bleeds, having inconsistent energy levels that meant I wasn't sure if she would be okay when we went out or if I would have to call someone or help her at any time. I also believe the number of failed kidney transplants she has had may be related to her HCV infection.

11. Having HCV has not only caused health complications for my mum, but has made it more difficult for her to get appropriate treatment for her other conditions. In 2017 she accidentally kicked a wooden beam and her foot became infected. Because the medication she needed in order to cure the infection was contraindicated with HCV, she was not able to take it, so the infection never healed. She developed gangrene and it spread up her leg. In the end she had to have her leg amputated above the knee. The doctors tried everything to save her leg, but they were not able to, and it was me who had to make the final decision to have it amputated. That is an awful decision to have to make for your own mother, to have

her leg amputated when she is only in her 50s. If she did not have HCV, that never would have happened.

12. It is now about a year after her amputation, and her amputation wound has still not healed due to the medication she is on. As a result she is not able to use her prosthetic leg and instead must use a wheelchair. This has severely restricted her mobility and lowered her quality of life.

13. As a result of the combination of having HCV and kidney failure, she has had to take many medications, some of them very harsh on her. She developed diabetes due to a medication she was on. Another medication caused her blood vessels to constrict, meaning that little blood could travel to her feet and hands.

14. As a result of all of the medications she has taken over the years, she is not the same person she was when I was younger. She is often on very strong painkillers, which means she can't focus very well. She struggles to manage her daily life, and can fall into depression and suicidal thoughts. If I am away from London for an extended period and there is no one to check on her, she can struggle to cope and sometimes put herself in danger due to poor eating habits and hoarding.

15. Although she has serious physical limitations, I would say that the psychological impact of having HCV has affected my mum even more than the physical impact. From the moment she was diagnosed, she has suffered from depression and shame about contracting the infection. She is also very anxious both about others perceptions of her due to being infected, and about the possibility that she could infect me or others.

16. Mum constantly feels she has to prove to people that she has never done drugs, because it is often the first thing they assume about her when they find out she has HCV. I remember even as a young child, being in hospital with her and hearing her explain to multiple doctors that she doesn't do drugs. She had to answer these questions on a weekly basis,

as she was sent to different doctors who didn't know her history and would immediately assume upon seeing her that she had contracted HCV through drugs, and questions like if she had any track marks. This has been damaging to her sense of self, and has left her feeling that no one believes her that the HCV isn't her fault.

17. Another thing that Mum really struggles with is that when she has been on dialysis she has had to dialyse in a separate room from the other patients because of the risk of infection. Dialysis is one of the only times that she gets out and socialises with people. Because it lasts four hours every few days and can be quite boring, the other patients often chat to each other to pass the time. It has really affected her self-esteem to be made to sit by herself in a side room instead of in the same room with the other patients. In addition, she has to walk through the main room past the other patients to get to the side room, so everyone knows she is being quarantined because she is infected with something and people sometimes comment or ask questions about it.

18. My mum received a course of interferon and ribavirin treatment for HCV in 2010. She had to stop the treatment after 12 weeks due to complications. While she was on this treatment, the side effects she experienced were comparable to chemotherapy. She was massively tired, weak, and felt like her body was being attacked from the inside out. It also affected her mood; it made her irritable and sometimes lash out, which was tough because it was just the two of us at home and I had to care for her while also being the target of her frustration.

19. She then went on a course of Harvoni treatment in 2016, which cleared the virus. During this treatment she had fatigue and muscle pain, but the most difficult aspect of this treatment for her was her anxiety about it. She became extremely anxious because she had been through treatment before and wasn't sure if it would work. She had also become more

educated about the infection, so she worried about the impact it could have on her body if she didn't clear it due to how long she had had it for.

20. I do think my mum should have been given treatment for her HCV much earlier. After being diagnosed in 1992, she then wasn't treated at all for HCV until 2010, and wasn't given Harvoni until 2016. I understand that her doctors were worried about the effect of any treatment on her kidney, but I also felt that the attitude of the doctors was that she was already ill because of the kidney issue and would just have to live with HCV for the rest of her life. As a result of that, they were very slow to consider treatment for her, and she had to keep begging them to look into it in order for that to progress.

21. Clearing the virus was a priority for my mum it because she wanted to be rid of it so that she could focus on her kidney problem, which could not be cured, and also because she was desperate to be rid of the stigma. But it was clear to me that treatment wasn't a priority for the doctors, because her liver wasn't showing signs of serious damage yet. They would constantly downplay what was going on with her liver and tell her there was nothing to worry about at the moment. It wasn't until she started to do research about HCV and its effects about 5 years ago that she realised she would have to clear it or it could seriously damage her liver; that information was never provided to her earlier.

22. My mum's infected status did impact her ability to be treated for other conditions. She had a lot of trouble finding a dentist that would treat her. By the time she did manage to get dental treatment, it was too late as the medication she was on had already ruined her teeth. To date, she has 1 natural tooth left on the bottom and uses dentures for her top teeth.

23. She also had trouble with certain doctors not wanting to perform investigations or operations on her because of the risk of infection.

24. My mum's infection has had a massive impact on her personal life. She has never felt she could date or have sexual relationships with anyone, as she feared their reaction if she disclosed her infection to them. She ended up only having one relationship in between my dad, who left when I was a baby, and now.

25. Although she had other health issues, it was having HCV that destroyed her mental health. It made her feel like a monster. Even though she has lost her leg, to date she is still more troubled and concerned about the HCV than any of her other, more physically limiting health problems.

26. Due to her limited mobility, her life has become very isolated. Her only social life is going to the supermarket and going to the hospital. When at the hospital she cannot even speak to other patients as she is quarantined in a separate room. If she had not had HCV, none of that would have happened. She wouldn't have lost her leg, she wouldn't have developed diabetes, and she would be able to manage her kidney problems like everyone else with kidney problems.

27. My mother's illness has dictated every aspect of my life from the time I was born. She was a single mum and I am her only child, so it was up to me to look after her if she became ill. Because of that, I basically had to become her carer from a young age, and I knew more than I should have known about her conditions because I had to know how to react if something happened to her. I remember being acutely aware of my mum's condition. The first time I called an ambulance for her was when I was six years old. She had had a nosebleed and because of the anti-coagulant medication she was on, she couldn't stop the bleeding and there was blood everywhere. I dealt with episodes like that on a regular basis.

28. As I grew older, I became her only advocate. I attended all of her appointments with her, took notes, pushed the doctors to give her the

right treatment, and made extremely difficult decisions such as whether to amputate her leg to save her life.

29. When I was very young, my mum was consumed with the idea that she could infect me with HCV. She gave me separate cutlery and toiletries and told me never to touch hers and to immediately notify her if I had. She also told me not to tell anyone she had HCV. I was constantly reminded to be careful and not to touch anything. She was so worried about infecting me that she would take me to the hospital every time she felt there was a chance I had touched or eaten something she had touched. As a result, I became very anxious. It made me feel like home wasn't a safe place, and that I always had to be on edge. It started to disrupt my whole life. I still struggle with symptoms of obsessive compulsive disorder related to cleanliness as a result of my mum's obsession with keeping everything clean.

30. As a child, I suffered from mental health problems as a result of the stress of caring for my mum. I had to see various therapists, was diagnosed with anxiety and depression, and took anti-depressants. It affected my sense of self-worth. Because of how ill my mum was, I felt like my life was consumed with just trying to survive and I didn't deserve anything more than that. It is really hard to get out of the headspace that you deserve less than anyone else because of the hardships you have had to endure.

31. Every decision I have ever made has been related to her illness, and I have not been able to explain any of it to friends due to the stigma. To live with such a taboo really messes up your whole way of being. Because we had to keep it secret, it felt like something to be ashamed of. I still feel undeserving and ashamed, it is something I have had to work really hard to try to fix.

32. As I grew older I worried that I wouldn't be able to care for her enough. I also felt subconsciously guilty that I had been the reason for her

infection, because she contracted it just after giving birth to me. I felt obligated to care for her to make up for it, and also because I was the only family she had. This pressure put a strain on my mental health, and on our relationship, as at certain points we started to resent each other.

33. When I was at school I was bullied because people found out my mum was ill and thought she was a drug addict. I got in fights, and people said horrible things about her. She would often not be able to pick me up from school if she was having dialysis, so people would make comments about me having a different person come to pickup all the time instead of a normal mum and dad, and ask if the person coming to pick me up was my mum's boyfriend. If she did show up, she was often tired or jaundiced and people could tell something wasn't right. Her absence, and her unexplained illness, made it look to others like my home life was a lot worse than it was.

34. I couldn't talk to my dad about what was going on. Although I saw him at weekends and we have a good relationship, he had his own family – a partner and another child – so he wasn't really involved with my mum's health issues. I felt I had to protect him by not telling him everything I was feeling about it.

35. There has been some tension in the family about my mum's illness. My grandad and uncle both gave her kidneys, and I think they were frustrated that these transplants were ultimately not successful and that this may have been related to the HCV. My mum's chronic illness also meant that other people in the family had to look after me more than they would have normally. I feel like I was brought up by a million people, and there were lots of logistical arrangements about how to look after me when she was in hospital or unable to care for me.

36. My mum's ill health has meant that she was unable to work, and we lived on benefits. Money was very tight when I was younger and we often had

to apply for various grants or schemes to get money for us to do the things that other kids could do, like go on trips at school.

37. I now work as an actor. While this is more flexible than an office job, it's also not as secure, and I have had to miss many opportunities in order to care for my mum. I often turn down jobs because there is no one to look after her. There was one opportunity recently that I really couldn't turn down because I needed the money, which required me to go to America for six months to work on a TV series. When I came back, her house was a serious risk to her safety. She had started hoarding things and could barely move around the house. Her room was not fit to sleep in, so she had started sleeping in my bed and had urinated in it. I feel like I can't stay away for too long because something might happen to her.

38. Because I have had to miss work so much, I have struggled to earn enough money to support myself. My work is not consistent, so I will earn enough for a few months and then have earned too much to qualify for benefits, but not be able to find work for six months. As work is already unpredictable it is hard to have to turn down opportunities when they do arise because of my mum, or to take opportunities I wouldn't normally take because they are closer to her. It makes me resentful of her, which I then feel bad about as none of this is her fault.

39. I also feel I have had to prioritise my mum over relationships and friends. I grew up with this "me and Mum against the world" mentality, which is unhealthy and has affected my relationships negatively. My most recent relationship was massively affected by the amount of time I had to give my mum. My partner said she felt like she wasn't in a real relationship as a result, and in the end this put so much stress on our relationship that it ended.

Section 6. Treatment/Care/Support

40. I have explained above how my mum faced difficulties obtaining treatment.

41. My mum has received counselling for depression but has not received any counselling from anyone specifically qualified in the area of HCV.

42. I have been seeing a counsellor for some time to work through issues arising out of my mother's health and my childhood. I still take antidepressants for this as well.

Section 7. Financial Assistance

43. Please see my mother's statement for details of her applications to EIBSS for financial assistance.

44. I do not feel that what she has been offered in terms of financial assistance has been enough. It has not been nearly enough to compensate her for what she has been through. In addition to her many physical complications, she has been made to feel subhuman. Her existence right now is not a life.

Section 8. Other Issues

45. I am glad that the Inquiry has brought to light this travesty. I want my mum to feel that she was listened to. I feel she at least deserves that, after being treated so horribly, made to feel suicidal and have bits of her body falling off.

46. In addition, my mum's illness has affected my whole life and my mental health. After what we have both been through it's really a surprise that we are still here.

47. I have concerns about the availability of my mum's medical records. Trying to find evidence of my mum's blood transfusion has been very difficult. We haven't been able to obtain her records from University College Hospital. I feel that after causing my mum so many health issues the least the NHS should do is be transparent and have a simple process for obtaining records. I understand that my solicitors have obtained records from Royal Free Hospital and my mum's GP but have not been able to obtain the University College hospital records either.

48. I am also concerned about how my mum has been treated by hospital and community professionals over the years. My mum is constantly not believed by social workers when something is wrong, and has to bring herself to hospital because they won't offer her assistance. I feel doctors see her as a burden; her current GP has tried to have her moved to another practice to avoid having to treat her. When she has tried to ask questions about the HCV over the years, she has always been ignored. And when she has been treated at the Royal Free Hospital, often things have gone wrong. Her kidney was scarred during a biopsy, doctors left a hole in her stomach when performing her latest kidney transplant, her leg had to be operated on multiple times before amputation, and multiple infections have been missed by doctors, resulting in them worsening significantly before being treated. I feel that my mum is not given the best medical care because professionals make judgments about how she got her infection and assume she is a drug user without looking into her history. Then when she tries to advocate for herself, they ignore her. After all of this, the least she should be entitled to is respect, assistance and adequate treatment.

Statement of Truth

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

Signed GRO-C

Dated …19 December 2019……….