

Witness Name: LUCY PARHAM

Statement No.: WITN0687001

Exhibits: WITN0687002

Dated: 18 January 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LUCY PARHAM

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 October 2018.

I, Lucy PARHAM, will say as follows: -

Section 1. Introduction

1. My name is Lucy PARHAM. My date of birth and address are known to the Inquiry. I am a married woman and live together with my husband, whom I met at University and got married to in March 2018.
2. I understand that my mother, Gill FYFFE has provided a statement to the Inquiry, which details the nature of her illness, how she came to be infected, and the subsequent consequences. Additionally, my father, Stanley, and elder brother, Rory, have also provided statements to the Inquiry which explain the impact that my mother's illness has had on them.

3. I do not, therefore, consider it necessary to repeat the information they have already provided to the Inquiry. In this statement I intend to speak about my mother's infection with Hepatitis C (HCV) and the impact it has had on me, along with my observations of the impact on the rest of the family.

Section 2. How Affected

4. How my mother became infected has already been recorded with my mother's and father's statements.

Section 3. Other Infections

5. My mum did not contract any infections other than HCV as a result of her blood transfusion. She did, however, and still does suffer significantly as a result of the infection and the treatment she received to cure her of HCV.

Section 4. Consent

6. The consent issue relating to my mother's infection has already been recorded with my mother's and father's statements. I have no knowledge of any consent issues relating to my mother's subsequent treatment.

Section 5. Impact

7. I understand that the many mental and physical effects of being infected with HCV and treated with Interferon have been discussed in the statements of the rest of my family. However, I would like to discuss some effects not previously mentioned.
8. Mum suffered severe memory loss, including on one occasion forgetting her own name in the supermarket and having to be

reminded of it. Her memory has largely returned but there was a period of time when I was a teenager where it was clear that Mum had forgotten large swathes of my childhood, which was distressing for both of us.

9. Since becoming photosensitive, Mum has been particularly anxious and concerned about family members being happy. She knows her illnesses have had a massive impact on everyone else's lives and can struggle to relax around us. This distresses her, adding to the burden of photosensitivity, and also requires us to regularly allay her concerns.
10. Whilst Mum was taking Interferon, she carried a stick with her, which had a folding seat she could sit on when she was out and became tired.
11. I have not been left with a very trusting sense when walking into a medical building. That being said, I don't believe I have ever been treated with prejudice by medical professionals as a result of Mum's infection.
12. Both Mum and Dad often only get five to six hours sleep in a 24 hour period (and sometimes as little as two hours) in part due to Mum's onerous skincare routine and in part due to the pressures of Dad's work as he attempts to provide for both of them alone. These brief hours are often not even taken in one block of time. Mum's extreme fatigue has been addressed in her statement but I think Dad's is somewhat overlooked.
13. Dad is suffering from extreme tiredness and his body takes any opportunity to sleep, regardless of whether he is sitting, standing, eating or talking. This is distressing to watch and I consider it a health emergency. The lack of compensation has forced Dad to work all hours of the day just to keep them financially stable. I believe that this

lack of sleep could send both my parents to an early grave. This danger would be, however, wholly avoidable if Mum and Dad were to be given proper financial support so Dad wouldn't need to work so hard. If assistance is withheld and the worst should happen, I will consider whoever withheld the assistance culpable.

Physically

14. Some of the physical effects have been recounted to me by my parents and indeed have been addressed in my Mum's statement. However, there are some which I recall. Those which have been recounted to me are the incidents when I was accidentally starved whilst still being breastfed, and when I was in a car crash when Mum fell asleep at the wheel. These incidents are both discussed in my Mum's statement.

15. However, I do recall an additional incident when I was approximately seven years old and I was falling asleep and cuddling in to Mum on the landing. A cup of boiling hot coffee was spilt down the back of my left calf due to Mum falling asleep whilst holding it, because of her extreme fatigue. I remember having to soak my tights off every night in the bath because the pus from my burn had soaked through my bandage and glued my tights to me. I also remember hearing the scissors clink on the bath as Mum cut the tights off and being aware that she was also cutting dead flesh off my leg. To me, at that age, my leg looked like lasagne.

Mentally

16. By far the biggest impact Mum's infection has had on me is the mental impact. The difficulty has always been that the story starts with me; everyone else in my family had a life pre-contamination but my life is encapsulated by Mum's transfusion. I say my life has been written in "contamination crayons". This reality makes me respond

very emotionally to the telling of the story and has made me anxious in anticipation of being interviewed by the Inquiry team, exacerbated by social anxiety, discussed later.

17. Usually, after speaking for a few minutes about Mum's infection to someone who doesn't know the story, I will feel low for several hours. This was particularly an issue when the book was published and we had to publicise it. The content of Mum's book has also reiterated this point: it starts with my birth and later Mum writes, "I started at the beginning. Our daughter is born."
18. For a long time, I couldn't attribute this feeling of sadness to anything. I have achieved lots in my life but if something goes wrong, I become upset to my core. Every thought is critical of myself and just becomes an additional hurdle to get over. I would talk about how I was feeling with my husband but we didn't make any progress as to what I was feeling or why.
19. I finally realised what was wrong with me one day early last year. I had called Mum because I had been feeling extremely down for two days and she said to phone back later when Rory and Zoe, who were visiting, had left. In the intervening time I was very upset, crying uncontrollably and wailing out loud, without knowing why. My husband returned home to help me.
20. When I called Mum back, Rory and Zoe were still there and the four of them were in heated discussions about how Mum and Dad were going to fund their old age. I knew this was important so I said I'd call again. I felt really sad that having to discuss this was causing everyone distress and I also felt really sad that I couldn't speak to any of my family when I was suffering so badly myself. The worst part was that I felt that they were upset over something I had caused.

21. My rational brain of course knew that this thought was erroneous, but I suddenly realised that because my Mum had received her infected blood transfusion at my birth, I had subconsciously linked my birth, my existence indeed, to Mum's illness and then the photosensitivity and financial struggles that ensued. I realised for the first time that I had been feeling guilty all these years.
22. I still find it hard not to think that if I hadn't been born, none of this would have happened to my family. When I manage to gain some perspective, I see that this is a silly thought and become angry instead that this erroneous guilt is something I have always had to live with and that my birth has been tainted by everything since. I think that I wouldn't feel this way if someone had taken responsibility for what happened to Mum and there hadn't been a cover up or the lies that have followed. I have to remind myself constantly that it is not my fault and unlink the fact of my birth from the fact of Mum's infected transfusion with thoughts such as 'if it had been an hour later, it would have been a different blood pack'.
23. Mum was diagnosed when I was seven and I remember going for our Hepatitis tests and not thinking at that time that it was a scary affair. I had no reason to suspect that my parents wouldn't be okay as they were always very upfront with us and they didn't seem scared. I now know they were being very brave so that we wouldn't be scared by seeing them scared.
24. I have suffered from social anxiety for around twenty years. I think this has been caused by two factors, firstly my erroneous feelings of guilt and secondly my sense growing up that Rory and I had different childhoods to other children we knew. The only time I haven't felt overly anxious in social situations was during my first year of University when nobody around me knew about my Mum's contaminated blood transfusion and our financial situation had improved with Mum working again.

25. Once Mum was diagnosed we would drive through to Edinburgh for Mum's hospital appointments. We would have long waits in coffee shops and Mum would frequently argue with Dad over the public payphone in the coffee shop. I recall feeling embarrassed that strangers could see us struggling.
26. I only had two changes of casual clothes, which were both hand-me-downs so I never felt like my clothes expressed me or even looked sensible. Nowadays, I have to be happy with my clothes or I start to panic. I recall on one occasion going to an event that Rory was at, at his school, and being given Dad's socks to wear because I didn't have any clean ones. I felt like everyone was looking at me all day and thinking how weird I was. When I went to boarding school, everyone had more clothes and possessions than me. I remember one girl taking pity on me and putting half her things on my desk so mine wouldn't look so bare.
27. Other ways in which Rory's childhood and mine were different from other children we knew is detailed later in this statement under 'Social Life.'
28. Consequently, I now become anxious anticipating social events. I often think that everyone hates me, is in cahoots and wishes I wasn't there. I frequently feel that there is something wrong with me and I dwell on the things I did "wrong" after any social event. My self-esteem always crashes during a social occasion and can take some time to recover once I'm alone, or with one or two "safe" people, again.
29. I always do things to ensure I don't attract attention to myself and avoid talking about myself. If I anticipate speaking in front of a group, I get a panicky feeling in my chest and a sore, twisted feeling in my

stomach, and I sometimes become tearful. I also frequently find myself taking responsibility for other people's moods.

30. These feelings make me self-conscious and are frustrating, particularly because I am naturally extroverted and am drawn to seek out company, and they make me feel hopeless about the possibility of changing and being free of social anxiety. When anxious, I feel that if people saw the "real me", they would be appalled.
31. In August 2018, I read a book about social anxiety and recognised this as what I was experiencing. I looked back on all the times I felt like that and when we were made to feel different to other children, which was only worsened when we went to boarding school.
32. I have only recently begun to talk about Mum's infection and the impact it has had on my mental health. The reactions of people are so strange that I don't bring it up. I think people get freaked out that something so terrible has happened to someone they know so could have happened or might yet happen to them too. This puts a barrier between my friends and me, worsened by my social anxiety. Because social anxiety is such an all-consuming feeling, I became moved at my hen party to see all my many friends together and appreciate that all the negative thoughts I had over the years couldn't possibly be true after all as I had so many friends there for me. I was also astonished and relieved my social anxiety hadn't pushed them away.

Emotionally

33. As a young child, it was very unsettling not knowing what would happen to Mum. I have a vivid memory of crying myself to sleep in the dorm at school in a rare indulgence of thinking about Mum's illness and about the fact that I didn't know what the outcome would be. This continued to affect me as I grew older and became an adult. I still live with the fear of the unknown. Mum's prognosis ten years ago would

have been a life expectancy of ten years, if she hadn't avoided light. Luckily, she seems to have slowed her decline, but we don't know to what extent.

34. I also remember going to stay a night at my prep school as a child, shortly after Mum was diagnosed, so that Mum could get a liver biopsy, and being scared for her and of being completely alone in the dark dorm. During my first year of boarding school, aged ten, I was very sad but did not express how I was feeling. I missed home terribly and missed my best friend. When I was 11, I became very paranoid and felt that I was in a Truman Show-type reality. On reflection, I realise now that this was the beginning of social anxiety affecting me. My paranoid feeling waned, but did continue to a lesser degree, until I was around 16 (when Mum had been cured of Hepatitis, and the photosensitivity had not yet developed).
35. At that age, I was desperately trying to make sense of all that had happened and tried to do so by painting Mum's portrait for my AS Level Art exam, a copy of which I exhibit as (WITN0687002). I used symbolic elements and included some extracts of Mum's poetry. Mum had been clear of Hepatitis for four years and I used it as a way of telling people outside the family what had happened.
36. The painting is a church-style stained glass window (Christianity was important to me growing up and I found some solace in the Church). The sun is in the top-right corner, and is a fiery, red and upset sun, signifying Mum's incipient photosensitivity. There is also a silhouette of Apollo, the god of the sun. I used red paint and coffee to create a substance that looked like blood to trickle down from the sun. The quotes I included from Mum's poems were: "But I saw her laugh as she laid down her sword", and: "There is a shame that sinners deserve but share with the sick". The first of these quotes was written about our family's mindset at the time of Mum's illness that you must never give up and the second was an observation that some people

react to illness as if it is the fault of the ill so as to distance themselves from sickness and alleviate their fear of becoming ill themselves. At the forefront of the painting is a white lily – the flower of death – and there is a ribbon, which is wrapped around the lily to represent the shape of the RNA of the Hepatitis C virus, which I had seen on Google. The bottom-left corner of the picture is textured to represent cirrhosis of the liver, and Mum's face is painted in the background of this.

Family life & HCV

37. As a very young child, Mum and Dad were routinely too tired to put us to bed and consequently we'd end up sleeping on the floor in front of the fire or in front of the radiator on the landing.
38. I also remember feeling like our days were the wrong way around. After numerous late nights, Mum and Dad would need to sleep and complete their regular household chores. We would wait in our beds for them to get us up, but sometimes Dad's mood or work would interfere with their routine and it would be dark again before we were up for the "day". Mum would give us bananas and biscuits to keep us going but if they stopped to cook us a proper meal it would be late in to the night before our "day" properly got started.
39. Food was always bought from the reduced to clear section of the supermarket and was often sugary, resulting in GRO-C needing multiple fillings. Breakfast would consist of half a tin of rice pudding for speed and low cost. Dinner was often cheese on toast. We were encouraged to eat a lot during our school lunch time to compensate. When I then went to boarding school, three proper meals a day was a novelty.
40. When we were at home, and after Mum's diagnosis, we would be sent to our rooms if she ever cut herself, whilst the room she was in was

bleached. We also were under strict instructions to avoid the fridge where mum kept her medication and the sharps box where her used needles were disposed of.

41. We also had a strict routine of hand washing. When we came home, we would have to wash our hands and show Mum. Mum and Dad would often argue in the middle of this routine (perhaps because Dad thought it was a step too far) and we would sometimes have to wait for up to an hour before our hands were checked. Dad's hands became very sore from washing them constantly. I was relieved to learn that my friend had to wash her hands before eating as it made me feel less different.
42. Once Mum's Interferon treatment began, our lives had to fit around her injections. We could never go away for longer than a night and had to cope with her effectively having the flu every second day or third day (she took three injections a week.)

Family life & Lupus

43. As Mum's photosensitivity worsened, we had to adapt to living in darkened rooms, with no heating on because it would worsen any autoimmune reactions and further damage Mum's skin. This also meant, and still means, that we have to have the windows open all the time, including in winter.
44. Mum also has to have the bathroom door open when she bathes. The bathroom light is too intense for her skin, so she bathes in darkness with only the light seeping in from the hall. When my now-husband began to stay over, we were stuck in my room behind a curtain (due to the location of the bathroom) whenever she took a bath. We also could not use the cooker as the heat could cause Mum's skin to flare up, so we had to time cooking with Mum's bath time. This meant we often ate late because an office emergency with Dad would mean her

bath time was delayed and, consequently, we wouldn't eat until after 10pm.

45. I used to regularly become annoyed when people would stare at or comment on Mum using a parasol or wearing a hat to avoid the light.
46. Mum's skincare routine is lengthy and repetitive. We have spent so many hours waiting for her to prepare her skin before we can do just about anything. It also takes its toll mentally on her and we have to spend time trying to cheer her up.
47. As an artist, I would love to paint Mum's portrait, but with the light issues, it just isn't possible.

Social life

48. A lack of official acknowledgement of the blood scandal makes it seem like it never happened. This makes it harder to discuss it with my peers, as many have never heard of it. When I do feel confident enough to discuss it, I quickly feel insecure, as it does not appear to be a credible story because it isn't something that is publicly understood.
49. I rarely talk with my friends about what has happened to our family and have never shared the true extent of how hard it has been. I realise now that it is beneficial for me to do so, but I still don't know how to, as some people act very strangely. I attribute this to people not really knowing what to say. Keeping it to myself all these years has had the effect of making it into a big secret that has been kept from everyone. When Mum's book was published, many friends got in touch to tell us they had never known. I think we've lost out on a lot of emotional support by trying not to burden others with it.

50. As a young child, it was hard to accept that some people, including a couple of family members, some friends and the dentist, didn't want to be in contact with us anymore but I knew that it was due to their ignorance, so I didn't let it bother me.
51. Mum was always concerned about whether she should disclose her diagnosis everywhere she went and the question distressed her. Fortunately, some good friends reassured her that this wasn't necessary. I do have some suspicions that not everyone believes that Mum is now photosensitive.
52. The diagnosis of HCV and subsequent photosensitivity were a lot for Mum and Dad to cope with. They were largely alone and the strain took its toll on Dad. He would frequently be in a bad mood, would purposely become a burden or engage in some repetitive game playing, which were clearly means of staving off reality for a while.
53. They frequently argued, but Mum couldn't just leave Dad to get over whatever was upsetting him. It was clear that we were better together as a unit working against Mum's illnesses, otherwise it was even harder to cope with. When we were young, Rory and I would have to sit and witness these arguments or, as we got older, try to help Dad find his courage again.
54. As children, we were always on high alert and had a number of responsibilities. Rory, being older, had to look after me as well as help Mum and Dad. Consequently, he seems to have developed extremely high standards for himself which, I think, has made him less confident in himself than he might otherwise be.
55. Mum and Dad's financial situation makes me concerned for the future and for any children I may have. If Mum and Dad can't support themselves financially, and we are then required to help them, then Mum's blood transfusion will affect a third generation of our family.

56. Mum's infection with HCV has had massive educational implications on me. We were late for school daily and would walk into assembly late and would often miss whole lessons to the point that when I changed schools, my best friend didn't notice I was missing until the third lesson. Our lateness was a major topic of conversation amongst people and I would feel uncomfortable knowing that we would be late but I was too young to do anything about it. To date, I still hate being late for things.
57. When we did arrive at school, we would often have wet socks and jumpers because Mum and Dad couldn't keep up with all the cleaning to keep the infection in check.
58. Our school also provided after school supervision for parents who couldn't make the end of school pick up time. We were often the last to leave and when Rory wasn't there because he had moved to boarding school, I was alone and painfully aware that it was me who was keeping the teacher at school.
59. Although I recognise the incredible benefits of attending a public school, being a boarder was not necessarily what Mum and Dad would have chosen for us and I don't think it helped with my social anxiety. I also bore in mind that I was only sent to board because Mum didn't want her illness to be our whole childhood and it was thought that Mum might die, at which point Dad would need help to raise us.
60. In sixth form, I became a day pupil due to my worsening anxiety, though at the time I did not have the knowledge to define this as the problem I was experiencing.
61. When I was in my final year of University at Oxford, I had to move in with my parents and brother in London, as there was no more money

to pay for my separate accommodation. I would spend four to five hours commuting each day, waking at 6am just to get to my classes on time.

62. I hoped to move back to Oxford for my exam season but by then none of my support systems were in Oxford so I decided to continue with my routine. In the final two weeks of my degree, I was examined more than I slept.
63. After finishing my degree, I had to help Mum with her research for the book. However, we would arrive at the British Library at Colindale just before it closed, which was a source of further embarrassment to me and solely due to Mum's extensive skin care routine.
64. Between 2014 and 2017, I studied at London Atelier of Representational Art (LARA) in London. It had started well, but I began to lag behind my peers due to having very little sleep. Often I was staying up late to type Mum's book. We had all agreed that it was important to help Mum to finish her book, both for the financial gain if it was published – in a climate where she could not maintain any other career due to being photosensitive – and because we wanted our stories to be heard, and didn't want those who we believe to have covered up what happened to get away with it. The other reason I would stay up late was because I wanted to wait up to see Mum in less pain once she had had her bath and spend time with her then.
65. I have also found working in an office after leaving LARA particularly difficult due to my social anxiety.

Section 6. Treatment/Care/Support

66. No counselling or psychological support has ever been made available to any of us. I don't know how efficacious it would be. It would be better, rather than to treat the symptoms, to address the

causal root of the psychological malady. An official and public recognition of the disaster has always been missing, but would help solve many psychological issues.

67. I have been made aware of the psychological support arranged by the Inquiry, and provided by the British Red Cross. I have made use of this and have since contacted my GP who has referred me for CBT.

Section 7. Financial Assistance

68. I understand that the financial assistance Mum has received is addressed in her statement.

Section 8. Other Issues

69. Like Rory and his wife, my husband and I arranged our wedding for a time of year when Mum could attend more comfortably. The way in which both my husband and Rory's wife have joined in with our family is amazing. Because of the infected transfusion, everything with our family is more involved than it would have been and seeing them react to our living situation was very reassuring because I had sometimes previously been worried that we were in denial and to blame for our difficulties.
70. I found it difficult adjusting to living with my husband and being able to go to bed at a more usual time. I would begin to feel tired at around 10 or 11pm and would want to go to bed, but would feel guilty because I knew my parents would still be awake, working and trying to avoid photosensitive reactions. This makes me feel heartless just for living a normal life. I feel the same about going out and partaking in recreational activities.
71. I think it is hard for most people to grasp the scale of who has been affected by this tragedy as the numbers are so large as to become

meaningless. As an artist I naturally think some public visual representation might help. An extra effort is needed to make this inquiry more in the public arena also.

Statement of Truth

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

Signed GRO-C

Dated 18 January 2019