

Witness Name: Rory FYFFE
Statement No.: WITN0688/001
Exhibits: **NIL**
Dated: 6 November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF RORY FYFFE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Rory FYFFE, will say as follows: -

Introduction

1. My name is Rory FYFFE. My date of birth and address are known to the Inquiry. I live with my wife Zoe who I married in 2013 though we have been together for the last 11 years. I have one sister Lucy, who is 3 years younger than me. I am a University graduate and I am currently employed as a production manager for the Edinburgh International Science Festival.
- 1.1. I am the eldest son of Gill and Stanley Fyffe. I intend to explain the impact that my mother's infection with Hepatitis C and her resultant photosensitivity had on my family.

How Infected

2. I am aware that both my father and mother have provided witness statements to the Inquiry. I do not feel it necessary to reiterate evidence regarding how my mother became infected. At the time of Lucy's birth I was only three years of age. I only became aware that something was not right as I got older. However, by the time Mum was diagnosed with Hepatitis C in 1995 I was 11 years old and had seen the change in her health. Even at that age I could understand the implications of the diagnosis.

Other Infections

3. Mum did not contract any infections other than Hepatitis C as a result of her blood transfusion.

Consent

4. I have no knowledge of any consent issues relating to my mother's infection or subsequent treatment.

Impact

Prior to Diagnosis

5. Before we received the blood test letter we shared the consensus that something was not right. Dad was self-employed, and Mum stayed at home looking after us kids. I just assumed it was difficult to be self-employed, times were hard, things seem to be difficult, family life in general was difficult. The situation was just not normal.
 - 5.1. When I think back we had got our assumptions of what was happening wrong. Everything was backwards to what we thought. We had assumed that Mum was fatigued because she was devoting all her energy to Dad's business, but after we received the letters with the blood test results we actually realised that things were other way around, Dad was putting all his energy into his work as well as supporting Mum who was just too exhausted to function properly.
 - 5.2. I can clearly remember how tired Mum was. It is best described as absolute fatigue. Mum was always pulling a chair over to sit by radiators. She was struggling to stay warm and would then fall asleep against the radiator. Being so fatigued she often suffered burns from the radiators and even from hot water bottles.
 - 5.3. We often slept on the floor of the landing. There was a radiator at the top of stairs on the landing, and Mum would have been sitting against or lying near it. My sister and I would have curled up next to Mum and we would fall asleep as well. Dad would come home from work expecting to see the kids in the bathroom brushing our teeth, but it didn't really happen. He would then try to wake us up to get us to bed but Lucy and I were young, and we were warm and sleepy and weren't being helpful.
 - 5.4. I know now Mum couldn't have got up. There is a marked distinction between fatigue and tiredness. There was an inability to carry out physical activity and process thoughts. Even though Dad would say normal things like 'let's get the kids into bed', Mum could not register it in her head and carry out the instructions. In the end Dad would fall asleep on the landing as well.
 - 5.5. I remember this period of time so well. I would have been 8 to 11 years of age. Lucy was 5 to 8. We were living in GRO-C I was at GRO-C School in St Andrews, Scotland.

5.6. A common theme at school was lateness. We were regularly late for school in the morning and late being picked up at the end of the school day. This was purely because we did not realise we were dealing with Mum's fatigue. You make a reasonable plan for how long things would take but they always took longer. I often missed parts of classes at the start of day. There was an awareness amongst my friends that we were always late; I wasn't bullied but I was teased because of being late. I often went to school with wet clothes. I guess Mum and Dad had a reasonable plan for housework, but it just didn't happen. Our clothes didn't get into the dryer in time.

Post Diagnosis

5.7. I was 11 when Mum was diagnosed with Hepatitis C. The treatment for the infection just made Mum's fatigue worse. There were nights that we slept in front of the fire downstairs as we didn't have central heating. We had moved into our house in GRO-C I was aged between 12 to 15 then. By this point we knew Mum was ill and so we knew the consequences and were better prepared to deal with it.

5.8. However, it was like Mum had the flu every other day. Mum had the injection and a few hours later would be bed-ridden with symptoms of flu. The drugs came in batches and you knew for the duration of the batch, we are talking 6 months at a time, we had to plan as a family which days Mum would be awake for. In our minds we were thinking 'If we start the drugs on this day, Mum would be awake for Christmas or if we start it on this day, then she would be awake for Lucy's birthday'. Everything had to be so carefully planned but for half of the time during the treatment, a period of 18 months to 2 years, we didn't have a Mum.

5.9. The other thing about the drugs was that they had to be kept in the fridge so any family activity that required leaving the house for a night had to be limited for a single night and had to be carefully choreographed. It was difficult when brains were not firing on all cylinders.

5.10. For example, something as simple as going on a weekend camping trip had to be planned properly. Dad would have the car packed, Lucy and I would put on our seatbelts and Mum would have her injection. From that point on, the clock was ticking. We would be thinking 'could we get there in time, set up the camp, pack up and get back home before next injection time kicks in or would Mum be too ill to function before then?' When Mum was taking her medication it completely dominated our lives.

5.11. During Mum's treatment I was really lucky to have received huge support from schools and colleges who identified the difficult situation we were in as a family.

5.12. Even through the treatment, Mum and Dad's driving force was to ensure that her contaminated blood did not affect the next generation. They have done admirably but you cannot get away from the fact that Mum had received an infected blood transfusion. It is always a part of our lives.

5.13. Once the treatment for her Hepatitis had finished life seemed to become normal. Mum had a lot more energy, Dad was working. Mum went to work at my school. All was good until the issues started with Mum's photo sensitivity.

Light Sensitivity

5.14. We had a situation where Mum was experiencing severe blisters and rashes. She developed swelling on her face and it was quite clear even to a layman that light was causing it. Mum went to the doctor to say she had developed a sensitivity to light and the doctor would parrot that back in Latin but wouldn't provide anything about what was causing it. I am not angry with the doctors but as I have a physics degree and have studied light I think I understand it better than the doctors. They couldn't give us much detail other than you are sensitive to light.

5.15. We undertook our own research, in terms of light causing the skin problems. We tried to associate the problem with the intensity and/or wavelength of light, if we could isolate the property of the light which triggered the reaction then Mum could still be able to operate indoors in adequate ambient light to function or watch TV or use a computer. We tried extensively to find a solution, but we have not been successful so far other than light avoidance. This illustrates how acutely sensitive Mum is to very small amounts of light.

5.16. St. Thomas' Hospital undertook some tests and informed us they hadn't concluded anything more detailed. They tried various frequencies, and wavelengths but from a physicist's point of view I think the experiment they did was flawed. All the intensities were so bright that they were guaranteed to get a reaction, so the standard test is not sufficient for Mum's case. The advice from the hospital was rigorous light avoidance but that is such a superficial statement as I don't think anyone can do that. They certainly cannot rigorously avoid light and hold down a job.

5.17. The cumulative effect of light on Mum is very apparent. Too much light one day means less tolerance the next. This made her working life impossible. I am not surprised that she had to give up work. I am surprised at how terrible the support from the welfare system is in response to her condition. She has been deemed ineligible for any form of support.

5.18. Not being able to access internet for its first 20 years or read a newspaper or watch a TV is very isolating. No one is aware of it but avoiding light is an incredibly difficult thing to do. The result is we don't have a solution, we have just reached a point where Mum is not in crises every day but the amount of ambient light that Mum can cope with is not enough to function properly.

Education

- 5.19. I made the wrong choice when I chose to do a degree in physics, looking back I should have done mechanical engineering. I would have been more motivated. I didn't have the motivation for physics, but Mum and Dad had been through so much I just felt I had to achieve something for them. Mum's situation made me get through it. I permanently have a lack of confidence and I can't really accept praise. I am anxious a lot.
- 5.20. Mum's health problems affected my romantic relationships. Before bringing a girlfriend home from university it was necessary to explain the realities of living with Mum's photosensitivity. Realities that must have seemed extremely peculiar, for example bathing with the bathroom door open as the light in the bathroom would have triggered a reaction.
- 5.21. I have been fortunate that two schools have taken it upon themselves to look after me and this is effectively all I have ever known so I therefore had a normal education as far as I was concerned. Despite school and parents' support, every single life decision I have made from a new shirt, to career, houses and family, each decision has been in a large part dependant on Mum's health and the effect of that on Dad's business and Mum's ability to work and generate income.
- 5.22. I went to boarding school which a lot of people would think was privileged. We went not because we chose to, but because the school looked after us when Mum could not. At that point, Mum couldn't get any more treatment as it had been deemed to have failed. We thought Mum only had a couple of years left and, as a boarder, I was away from home. I was on the phone to her every night. It was terrifying.

Psychological Impact

- 5.23. I think Mum's illness has had less an effect on me mentally than on Lucy and I put that down to the fact that I had a couple of years on Lucy, so I understood it better and that inspired confidence. I think it has had a damaging effect on Lucy's mental health, so I feel quite fortunate that I have avoided that.
- 5.24. There have been a huge number of stresses. Probably about once a month we have all sat up all night trying to work out things financially and how to make everything work, for example our living situation. That has a physical exhausting effect and those situations are always emotionally charged and damaging to all the relationships. The next day you would think I don't want it to kick-off again, so I wouldn't call home, I just don't want to lose the whole night again. From an outside point of view it would be perceived as an argument, but it is actually people putting their views across passionately.

Stigma

- 5.25. There was some stigma associated with Mum's illness. There were some families in St. Andrews and some members of our own extended family that

cut off communication. They didn't want their kids coming around to play or didn't want our families to meet up at Christmas. We were ostracized. I don't think there was any evil intention but if someone came around and Mum got a paper cut then it suddenly became an infection control situation 'stay in the room and don't come out until Mum sorted it and bleached the house'. For an early teenager, that was a notable experience that was talked about at school. I remember well 'Rory's weird family.'

- 5.26. I definitely didn't get the correct dental care from the dentist at St. Andrews who gave me the all clear. When we moved to Edinburgh I was told that my teeth were awful. I am still having problems sorted out now that shouldn't have been allowed to develop because a dentist was worried about catching Hepatitis from the son of someone of who was infected. I am not going to have all my teeth by the time I am Mum and Dad's age.

Treatment/Care/Support

6. As far as the treatment for Hepatitis C is concerned I was too young to have understood what other options could have been offered.
- 6.1. At no point has any member of the NHS or Department of Health stuck their neck out and publicly acknowledged the evidence, that photosensitivity is a side effect of interferon. Consequently they have closed off potential investigative avenues by not exploring evidential links. Medical professionals have shut off conversations we have had with them about Mum's condition. There could have been more collaboration, I do not know of a treatment that would have made a difference, but we could have had more collaboration.
- 6.2. Doctors have medical expertise, but due my studies and my degree I know more about light and how it can impact on a person. Had there been collaboration then as a team we could have found a solution, but the medical professionals just don't wish to engage or acknowledge the problem. If there was just an acknowledgement then that would indicate a shift in culture, to identifying problems and accepting fault and then who knows what treatment there would have been for this.

Financial Assistance

7. I am not aware of the financial assistance Mum has received but understand this is addressed in her statement.

Other Issues

8. It is difficult enough for employers to make reasonable adjustments for people with visible problems never mind something that isn't so obvious. As a family we have made major changes to support Mum. We all use low level lighting whenever she is around. We even had to change our wedding plans to ensure Mum could attend.

- 8.1. It may look like we as a family have succeeded but all we have done is shift problems into the future. There has been a cycle of better times where Mum and Dad worked and were able to buy a house and then bad times where they had to sell them, but that system only works where you have infinite earning years. This is not the case for Mum and Dad. They have sacrificed everything for Lucy and I and now we have to plan to look after them in their old age as they have large debts and no savings, property, pensions or life insurance.
- 8.2. Zoe and I left London a year ago with intention of getting away from the big city and starting a family. GRO-C
GRO-C Zoe and I support and applaud Mum and Dad with their intention to ensure the infected transfusion does not affect the next generation. Sadly Zoe and I must also make plans to support them financially in their old age, consequently our plan to have kids is being impacted. From a financial perspective, Mum and Dad don't own a house, don't have adequate pension and don't have a reliable financial plan. Their financial situation now relies on Mum not only selling books but becoming a considerably successful author; that is the only plan open to us due to Mum's health caused by the side effects of Interferon.
- 8.3. However, as a backup, we need to have resources put aside to support Mum and Dad and it wouldn't have been the case if Mum hadn't been given a contaminated transfusion. There is no doubt in my mind that Mum would have been a Deputy Head at school and then a Headmistress by now. Dad was at director-level, and these roles come with a healthy salary and accommodation, but he became self-employed, so he could look after Mum. They owned houses but had to sell them just so they had the money. Zoe and I would have been in a situation where we could have been in a strong position to make choices in our lives. We both have degrees from good universities. Even today Mum's illness impacts on our choices.
- 8.4. We have to have self-confidence and self-belief. We have accepted help but always felt it is our responsibility to get ourselves out of this situation. We continually have family discussions but there is no answer. Fortunately, we are a close-knit family and in the end all we can do is keep trying to find a cure. I don't have faith in our medical system helping.

Statement of Truth

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

Signed GRO-C _____

Dated 06/11/2018