

Witness Name: STANLEY FYFFE
Statement No.: WITN0686/001
Exhibits: NIL
Dated: 17 October 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STANLEY FYFFE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 02 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, STANLEY FYFFE, will say as follows: -

Introduction

- 1.1. My name is Stanley FYFFE. My date of birth and address are known to the Inquiry. I live at home with my wife, Gill, and have two children, Rory born in 1985 and Lucy born in 1988.
- 1.2. I am a Chartered Engineer and have run my own business as a sole trader since 1989. I now work from home to accommodate Gill's illness.

How Affected

2. Gill and I met at school, though I was two school years her senior. We were married on 18th September 1980 and have now been married for 38 years.
- 2.1. On GRO-C 1988, at 41 weeks' gestation, Gill was induced at Ninewells Hospital, Dundee. Lucy was born via forceps delivery in the early hours of GRO-C 1988.
- 2.2. It was a difficult birth, complicated by the fact that the labour suite seemed to either be particularly busy or understaffed, but certainly not in a position to cope with what was going on. The doctor seemed experienced, though I am unsure of his exact rank. However, he was rushing between the

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mothers who were in labour and there was a definite degree of urgency in the labour suite.

- 2.3. At some point, it was decided that an epidural would be administered to Gill, but this was botched in some way and left her in a great deal of pain during Lucy's birth. I was present throughout and involved to some extent in helping ease the pain, though cannot now recall my exact role.
- 2.4. Lucy was delivered with the aid of forceps, and then the doctor had to revert to attending the other women. When he returned, he was very unhappy to discover that the injection required to help Gill deliver the placenta had been administered incorrectly. We were told that it couldn't be repeated and that a manual extraction of the placenta was therefore required.
- 2.5. The only word I can use to explain this procedure is "brutal". One of the Doctor's hands was inside Gill's womb whilst the other pummelled and pounded on her stomach.
- 2.6. Some time thereafter I went to check on Rory at Gill's parents house. I cannot recall if I was called back to the hospital or attended there anyway, but I was made aware upon my arrival that Gill had lost a lot of blood during or subsequent to the placenta removal. The doctors were minded to give her a transfusion to replace the blood she had lost.
- 2.7. I seem to remember that at the time of being made aware of Gill being asked to accept a transfusion, she had already resisted receiving it. Both Gill and I are very analytical people, and assessed the options together, whilst bearing in mind what the doctor had said.
- 2.8. We were initially told that all that was required was bed rest to allow Gill's body to replace the lost blood, so we agreed that bed rest would be the best course of action – we were generally of the opinion that you shouldn't accept a transfusion unless it was absolutely essential. We were both aware of HIV or AIDS and considered it to be an avoidable risk.
- 2.9. I once again left the hospital, but was summoned back and recall being perturbed at Gill's appearance; she was very pale and lying in bed. We were again told that bed rest was all that was necessary to promote her recovery, but the doctor was still insisting on a transfusion.
- 2.10. We reiterated that unless it was an emergency, we would not accept a transfusion. It was at this point that the tack changed, and the line was taken that if Gill haemorrhaged in the night, they would not be able to transfuse her quickly enough to keep her alive. With that information borne in mind, I asked Gill to accept the transfusion.
- 2.11. There was a great deal of discussion as to the safety of the blood and as an engineer, I understood the concept that no blood can be totally safe, yet was assured that this was the case. Given that we had been told it was now an emergency, we consented to the transfusion.

- 2.12. When I visited Gill the next day, she was hooked up to the machine. I asked her if they had begun the procedure the night before, to which she replied that they had just started it. This really upset me; I can't remember the manifestations of my upset but the transfusion was meant to be a life saving procedure and I felt we had been deceived.
- 2.13. I became more upset at the fact that every time the medical staff were handling the blood packs, they were wearing gloves; it seemed ironic that they were assuring us it was totally safe, yet wouldn't go near it without the gloves.
- 2.14. We were both upset by the hospital experience and wanted Gill out as soon as possible. She was in no way fit to leave, but with my help she was able to leave.
- 2.15. In retrospect, we agreed to a low, long-term risk to Gill in order to stop what we were told was a very dangerous emergency situation. The next morning, I no longer believed that it had been an emergency situation and still fully believe that it was done either for the convenience of the hospital or for the protection of the people who had made such a bad job of Lucy's delivery.
- 2.16. I now think we were tricked into consenting to a high risk blood transfusion in a non-emergency situation and I have felt angry about this ever since.
- 2.17. At some point during the process of the transfusion, we learned about the risk of Hepatitis, but had no idea what it was. The risk of AIDS overshadowed this so we gave Hepatitis no thought.
- 2.18. I don't think the answer we gave to the doctor was wrong at the time, but I don't think the facts with which we were presented were correct. We were in fact cheated. Given that the doctors were authorised to give the transfusion immediately for the specific purpose of saving Gill overnight, whenever they decided not to do that, they should have reverted to us before taking further and unauthorised action.
- 2.19. I don't feel guilty, as I believe I responded in the way I should have at the time, but I am upset. Gill is very strong minded, and she and I did everything we could not to have that transfusion. My only regret comes from having persuaded Gill, based on the information we had been provided, to accept the transfusion.
- 2.20. I think Gill and I came as close to being forced to accept the blood as was possible. We were conned into accepting it and feel that the doctors on duty had searched for something to say to make us inclined to accept the blood without warning us of the risk.
- 2.21. Gill received her transfusion on the morning of the 9th October 1988. As a result of it, she contracted Hepatitis C.

- 2.22. Gill received a letter in November 1995 warning her of the possibility of being infected with Hepatitis C. My only recollections are of receiving the letter and then totally dismissing it. I didn't really read it but Gill immediately knew she had the disease, as this explained the years of fatigue from which she had been suffering.
- 2.23. We later found out that our GP had been asked to pass on the news but that he was unhappy about doing this, so he insisted that the Blood Transfusion Service should be the ones to inform her of the infection.
- 2.24. We were told that it was possible that the children and I could be infected and we were tested right away. The results arrived in a matter of days. In that respect, the GP acted quickly and in a manner we were happy with. Thereafter, the GP was very helpful. As he didn't know much about Hepatitis C he did some internet research which enabled us to look into it ourselves.
- 2.25. We found out that Hepatitis C is a disease, which causes cirrhosis, cancer and death. We have only recently learned that the virus causing Hepatitis actually attacks all sorts of parts of the body and is only called Hepatitis because it is initially most noticeable in the liver.
- 2.26. We were advised by our GP that we may not want to tell anybody because of the stigma associated with Hepatitis C. We discussed this and dismissed the notion quickly.
- 2.27. We later received instructions at the clinic for liver disorders that Gill must take care not to transmit her illness to other people. The things they were asking her to do were impractical and would have left her constantly bleaching surfaces around her. There seemed to be no real understanding by the nurses as to how these precautions would be implemented in normal life. We took many precautions but can't say if we took too many or too few as the people providing the advice didn't really have an understanding of the risks of transmission or practicalities of the advice they were giving.

Other Infections

3. Gill was not infected with any illness other than Hepatitis C as a result of her blood transfusion.

Consent

4. Gill gave her consent to receiving Ribavirin, which was an unlicensed drug being tested as part of a research project. She had to sign a waiver not to pursue legal action in the event of an adverse reaction to it. I believe this waiver to be void as explained in 6 below.
- 4.1. Upon reviewing Gill's medical records, we now suspect that Gill was enrolled in an HCV Lookback programme in December 1995 without her

knowledge or consent. Her GP has filled in paperwork related to this Lookback programme but we were not involved in this.

Impact

5. Upon receiving the transfusion, and prior to receiving treatment for Hepatitis C, Gill was so tired and disabled that she often couldn't stay awake through the evening. She would be too tired to put the children to bed and I would frequently find her asleep on the landing with the children. At this point, she was quite difficult to deal with in her tiredness and would be very upset when I tried to waken her. On many occasions I gave up and we all slept on the floor.
 - 5.1. Due to her fatigue, she would often be late to work and the children late to school, to the point where we received a concerned letter from the headmaster. We became scared that the children would be taken away from us if people didn't think we were good parents. Gill exhausted herself further trying to give the children a childhood – she lost a lot of time with them because of her illness and treatment.
 - 5.2. The treatment with Interferon was awful: we were told that a lot of people didn't cope with the treatment at all and gave it up because of how bad it made them feel. We thought this might be because of them living chaotic lives so we were rigorous in getting everything right with Gill's treatment.
 - 5.3. We were willing to do anything (including taking the experimental drug regime as the alternative appeared to be a descent in Gill's health leading to premature death). There was talk by the doctors of the high cost of treatment. I believe that this was the main reason that they were reluctant to attempt a second round of treatment when the first failed.
 - 5.4. The second round of treatment did appear successful, and Gill quickly regained her vitality; she returned to working full-time whilst studying for her MLitt concurrently. She became a housemaster quickly and was beginning to get back to the position she would have been in, but for the Hepatitis C infection.
 - 5.5. Although Gill had gained back the energy she had previously lost, the major adverse effect of taking Interferon is that Gill developed photosensitivity and other symptoms of what we now know is auto-immune disease (SLE). This progressively worsened over the years following the conclusion of her Interferon treatment.
 - 5.6. Initially, it was thought that it was her childhood eczema making a recurrence, so there was an effort by her GP to try to resolve this. However, the autoimmune disease increasingly inhibited her, to the point where she once again had to retire from teaching.

- 5.7. Light sensitivity is particularly difficult to deal with in terms of perception as Gill appears quite well outwardly. If she didn't take as much care as she does to avoid light, she would suddenly become quite unwell.
- 5.8. Gill was given a light sensitivity test at St Thomas' Hospital. The results of this were unhelpful. The doctors established that she had an abnormal reaction to some wavelength contained in daylight, but couldn't specify which one it was.
- 5.9. Throughout Gill's illness, we have found we can only maintain one career at any time. When one of our careers began to do well, the other lagged. We found ourselves permanently in crisis mode: the more Gill tried to work, the more I had to support her and the less work I could do.
- 5.10. Consequently, my own career prospects have been hindered by Gill's Hepatitis C infection. We have not been able to invest the time and money needed to develop my business and as such it is not in the position we feel it would be in if Gill had been well. I work hard just to make ends meet.
- 5.11. We have not experienced a great deal of stigma associated with Gill's illness; our friends in St. Andrews were an intelligent group of people and very worldly and as such did not treat us any differently. Sadly, two or three relatives stopped visiting and seeing us.
- 5.12. Gill was badly treated by one dentist, who thought that by treating her, he would be placing all his patients at risk of infection. Upon a call from the British Dental Association, he was forced to treat Gill, but did so by covering all surfaces with cling film prior to treating her.
- 5.13. Gill was so concerned about infecting me that we did not have a sexual relationship from the time she was informed of her infection until years after she was pronounced clear.
- 5.14. The work-related effects of Gill's diagnosis cannot be overstated. We have both had to make serious compromises as the nature and volume of work we undertake. Gill had a very promising career as an academic ahead of her but is now permanently unable to work.

Treatment/Care/Support

6. Gill was offered the second course of treatment (Interferon with Ribavirin) on the proviso that she signed a waiver not to pursue legal action for any adverse reaction she may have in consequence of receiving an unlicensed drug. I, however, believe that the need for treatment was a direct consequence of receiving the contaminated blood transfusion and, as such, the waiver is void.
- 6.1. Neither Gill nor I have received counselling or psychological support in consequence of her infection with Hepatitis C.

Financial Assistance

7. Gill has also provided a statement to the Inquiry and has discussed the financial assistance she has received from Trusts and Funds set up to distribute payments.

Other Issues

8. Despite Gill's autoimmune disease being a well-documented side effect of Interferon treatment, she is yet to meet a doctor who has categorically said that her auto-immune disease is a result of her treatment with Interferon. Very few doctors are sympathetic and are indeed very matter of fact about her illness. There seems to be either, a general lack of lateral thinking in the medical profession or a general desire to avoid any suggestion of blame.

Statement of Truth

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

Signed _____ **GRO-C** _____

Dated *17 October 2018*