



Witness Name: Shelagh O'shea

Statement No.: WITN0043-001

Exhibits: WITN0043/002
WITN0043/003

Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SHELAGH O'SHEA

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 September 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I have been asked if I am legally represented and I can confirm that I am not. My son, Luke O'Shea-Phillips, is represented by Collins Solicitors.

I, SHELAGH O'SHEA, will say as follows: -

Introduction

1. My name is SHELAGH O'SHEA. My date of birth and address are known to the Inquiry. I have had a partner for 28 years but we do not live together. I live alone. I intend to speak about my son, Luke O'Shea-Phillips, who was diagnosed at the age of 1 as a mild haemophiliac (Type A). He was subsequently given Factor VIII blood products which contained the infection Hepatitis C.
- 1.1. I will go into detail on the nature of his illness, how the illness affected us, the treatment received and the impact it had on us and our lives together.
- 1.2. In order to help me with this procedure I have drawn up a sequence of events, a copy of which has been made and supplied to the inquiry. WITN0043/003.

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How Infected

2. In 1982 I was living in Brighton and Luke was 1 year old when he was diagnosed with haemophilia. GRO-C
- GRO-C I knew that I was probably a carrier. We moved to London and I signed Luke up with the Middlesex Hospital, now the University College London (UCL) Haematology Department. Luke was under the care of a Professor from 1984.
- 2.1. Luke was treated on three separate occasions. On the 15th May 1985, Luke was treated at the Middlesex Hospital following an injury to his mouth. He was treated again on the 21st December 1987 following a nosebleed. On the 24th November 1989, Luke received treatment at the Shrewsbury Hospital after a trauma to his knee. On those occasions he was given Factor VIII blood products and subsequently was infected with Hepatitis C.
- 2.2. I know from Luke's medical notes that the injury to his mouth was intermittently bleeding for 3 days. An infusion DDAVP had not controlled it and so Luke received 1,680 units of Alpha heat treated FVIII concentrate. The notes do state that Luke received propylate **list number 360210, lot number A6-0311**. At this time, Luke was under the care of Professor Machin.
- 2.3. At the time Luke was given the Factor VIII product, there were no discussions with me about the risk of him being exposed to infections. It was just a matter of course that Luke will need FVIII and that is what they will give him. There was absolutely no discussion about the product being dangerous. Had that been the case, I would have gone away and had a discussion with Luke's Dad and my mother. His injury was not life threatening, so I would not have put Luke through something that would have endangered his life. He was 3 years old. He is my only child. There was no discussion. It was just a process; he is bleeding and the next day it was FVIII. That is what it was.
- 2.4. Luke was clear on all the tests, from what I could see, apart from Hepatitis C. I only became aware that Luke had been infected with Hepatitis C by a letter dated 6th January 1997 that was addressed to me and received from the Consultant Haematologist Dr. Mike Laffan. The purpose of the letter was to remind me that Luke was infected. The letter read as follows: *'you will remember that Luke has acquired Hepatitis C infection at some time in the past and I think it is important that we keep this under review. There are some blood tests which we should monitor and I would like to discuss the pros and cons of treatment with you again.'*
- 2.5. I have given a copy of this letter to Paul Batey and I exhibit this as **WITN0043/002**.

- 2.6. When I got this letter that Friday evening I was meeting my partner and I brought the letter with me. You have such high regard for a consultant that I completely doubted myself and thought I must have forgotten. But I knew I would not have known about Luke's infection and then not told my partner. So I brought it and told him I had got this letter from the hospital. He looked at me like - I'll never forget - he just could not believe it. It was shocking. He was shocked. I was shocked. We were shocked. I did not know what Hepatitis C was and did not know where my son had got it.
- 2.7. I was not given any information in order for me to understand and manage the infection. I later relied on a book (the Hepatitis C Handbook) which I sourced myself. I quickly realised that we needed to be careful around other people because it was blood borne. I do not know when Luke was finally diagnosed with Hepatitis C. They were testing him all the time unbeknownst to us and so, as soon as they found he had contracted Hepatitis C, that was the time when we should have been informed and advice offered.
- 2.8. On Luke's notes it always says 'danger of infection', but no one told me there was danger of infection. We just kept being called in for various tests. The blood test requests from Luke's consultants to the laboratory regularly carried a warning that there was a danger of infection from Luke's blood samples. I don't understand why the laboratory was routinely alerted to the potential hazards of dealing with his blood whilst I, as his mother was kept in ignorance?
- 2.9. I was not informed until 1997. The earliest reference in the notes confirming Luke's Hepatitis C is in 1995. Luke was admitted to hospital in November 1993 and I know they knew then because Luke's hospital admission notes of November 1993 show, 'Hepatitis C, further stating, *'mother doesn't know' (notes say 'patient and family unaware at present'). Further, there are entries recorded in October 1993 stating: 'HCV antibodies; yes. Hepatitis booklet given; nothing entered. Discussed with patient: no'.*
- 2.10. So somewhere prior to 1993 Luke was diagnosed, but it was not until 1997 that I was informed. I should have been told. Luke should have been protected. In 1995 Luke was 15 going on 16. Potentially, he could have been sexually active. Luke was not afforded that right to protect other people.
- 2.11. Luke's infection was communicated in the most patronising and condescending way. It was unbelievable that a Consultant Haematologist would have such little respect for another human being to write something like that to us in a letter. They must have known that letter was going to arrive with me on a Friday so that I could not get hold of them for the whole weekend. I have become cynical and believe it was stage managed. They were utterly in denial.

- 2.12. I did not tell Luke. On the Monday I phoned the hospital and demanded to see Dr. Laffan. I said that he needed to tell Luke, not me. Luke and I then went to hospital the next day and Dr. Laffan explained the condition to Luke; that there was no cure. I never voiced my anger at Dr. Laffan for what he did because I went from being in a state of shock, to protect mode. I had to protect Luke and put my energy into that.
- 2.13. Dr. Laffan maintained that he had previously told me. Arrogance !. I told Dr. Laffan that he had not previously told me. He blustered "we need to move on, we need to get this sorted". It was them versus a single mother with a sick child who was having a meltdown. There was no recourse to anything and I just wanted to get Luke sorted. I feel so angry with myself for being so naïve and so trusting of them.

Other Infections

3. I have been asked if Luke received any infections other than Hepatitis C as a result of being given infected blood products. I can confirm that the answer to that is no.

Consent

4. Because of Luke's age at the time, my consent would have been required for any treatment or testing. Luke was being tested from the 13th November 1984 without my consent or knowledge. I refer to his medical notes where there is an entry dated 13 November 1984 which records 'blood sample for haemophilia – mild' and 'urgent test for HIV/HB. Has received no blood products'.
- 4.1. I was under the impression that Luke was being tested just for haemophilia and had no idea of any other tests taking place. We were called back for other blood tests over a period of about a year and then Luke had his first bleed.
- 4.2. I have seen in Luke's medical notes a letter dated 12th June 1985, from Dr. Machin to a Doctor at the Royal Free Hospital. The letter is dated after Luke received treatment on the 15th May 1985 for his mouth injury. The letter mentions Dr. Machin having treated "two 'virgin' haemophiliacs with Alpha heat treated FVIII". It then gives the details of the two patients, one being Luke.
- 4.3. The letter states 'both patients will attend for fortnightly follow up blood samples, for liver function tests, blood count and virology. I hope they will be suitable for the heat treated trial.' This letter was copied to a male possibly working for Alpha Therapeutics.

- 4.4. I have also seen in Luke's medical notes a letter dated the 22nd June 1993 from Dr. Machin to a Doctor of the Ealing Health Authority. In this letter he discusses Luke and says that 'he has been under his care since March 1985 when a diagnosis of mild haemophilia A was made. 'Since that time he has required treatment with high purity Factor VIII concentrate on only one or two occasions per year. You will be pleased to hear that he is fortunately HIV negative and he has completely normal liver function tests. On examination everything is completely within normal limits, including a complete range of muscle and joint movements. Obviously any bleeding episode should be treated by an infusion of Factor VIII concentrate. For this he attends my clinic here at the University College Hospital and apart from that I only see him annually to review his progress.'

Impact

5. I have been asked to describe the impact Luke's infection had on myself and Luke. I can only speak as his mother, it badly affected our relationship. The impact of discovering, at 15 years of age, that he had this condition that he was going to die from and for which there was no guaranteed cure, just knocked him back. It completely changed his attitude towards life. Luke just withdrew, became very depressed and anxious. I lost him.
- 5.1. Luke became very angry. I think at some level Luke is still angry at me because I did not protect him. He went off the rails. His deterioration was prolonged. Luke ended up exhibiting very anti-social behaviour when he was about 30 years old and the anger just seemed to eat away at him. Luke found relationships difficult. I thought he was gambling. I didn't know what was going on with him. It was getting worse and worse. It was horrible.
- 5.2. Luke's infection also impacted his relationships with women. He was terrified the disease would come back. It was a horrible time. He was taking a horrible combination of drugs. He was isolated. Luke had some good friends who would visit, but otherwise he was out of circulation.
- 5.3. Even after he was cured he would not believe it. They were not able to tell him whether it would come back. There was no definitive 'it is over'. Living with that fear has an impact on one's wellbeing. It certainly did on Luke. Forming relationships was difficult for him and he found it difficult to have long term relationships. He eventually met his wife and it was very difficult for them to talk about. Luke didn't have the infection but it was like it could come back at any moment.

- 5.4. Luke was going off to sexual health clinics to get himself tested, which he told me was not pleasant. But it was just because he didn't believe and didn't have confidence. Luke and his wife had to tell her parents and they were absolutely horrified. They didn't want her to marry him. That was really difficult as well. That was more stuff that he had to deal with.
- 5.5. Luke was 15 when he was diagnosed and, eventually, at the age of 22 was treated with Interferon and Ribavirin. That was a 4 year and 9 month wait which I think was due to his age and money. It was stalled and stalled, until eventually Luke was given permission from the Royal Free Hospital, by a Doctor.
- 5.6. While Luke was taking his medication he became very tired and he needed to take time off work. It was a hard year for him but he just got on with it. It took a number of years for him to get back to normality of any sort.
- 5.7. Because of Luke's infection, he has not received dental treatment that anybody else would get. In fact I think Luke avoided the dentist.
- 5.8. Growing up, Luke was a very popular young man who was very much into acting, drama and was always the lead part in the school show. He was very confident and, despite his haemophilia, I was determined that he would just live a normal life.

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 Luke lived a very full life. However, when Luke was diagnosed he lost interest in all the things that he loved; football, theatre, music.
- 5.9. I had a very different attitude to his diagnosis. I went into practical mode. I had to suspend everything that I was feeling. I was following the Hepatitis C Handbook I had sourced. I was researching Chinese medicine. We were going off to acupuncture. We were going to fight this. It became 'the thing' that I did to make him better. I think it did have an impact on him. He felt that something was happening for him, because nothing else was. We would have just been sitting at home otherwise. So that is how I dealt with it. The emotional bit I just left off, which was perhaps not the best thing to do, but that is how I treated it.
- 5.10. I was working full time, with a child, so my social life was not the best anyway. However, for the year that Luke was undergoing treatment my social life was certainly interrupted because it was a whole year of him at home needing to be looked after.
- 5.11. I had continued working but nobody knew what was going on for me. I heard about his diagnosis in the January. I was Deputy of my school at the time. In March my Head told me he was leaving. I did not say anything to anybody at work. I had to get on with it. I took over the Headship and I didn't tell anybody about the distress and torment I

was feeling. It was a very difficult time for me personally and at work, having to manage it all.

- 5.12. I didn't have time to adjust to having a very sick son. I was now having to step up to a new role and manage those two things. It was very stressful. Now is the first time anybody has even been aware. I haven't been in school much this week so I told some people. My life would have been easier work wise if I did not have to cope with the shock, trauma and disintegration of my son. My career would have been a lot easier than it has been. It was a very lonely time. I was on my own. My partner lives in a different city. It was lonely.
- 5.13. My partner has been very supportive and there has been no impact on our relationship.
- 5.14. Luke's infection was not something that we talked about easily. Luke didn't want people to know. I didn't know what the infection was but very quickly discovered that it was 'associated' with needles and drugs and things that were seen to be unacceptable. It was not until Luke started treatment that he came clear about what was happening to him. However, by that time, there was a greater understanding in the community about it. I am not aware of Luke having suffered personal abuse.
- 5.15. I have previously mentioned the impact on Luke's school life. In recent times he has done very well. He works at the BBC and is now a manager. He completed 6th form at Richmond College. After college he did various sorts of jobs, such as a porter. Although he worked, he did not have a sense of purpose at all. Eventually, having seen an advert in the newspaper which I mentioned to Luke, he was subsequently offered a job at the BBC. Since starting his post at the BBC, Luke has worked his way up and now has a managerial position.
- 5.16. The BBC were helpful and made adjustments for him when he was working through his treatment. He was very sick for a lot of the days. In his file there is a whole thing about the days that he missed. They did try to adapt the work for him so that he could continue working. He did not lose his job.

Treatment/Care/Support

6. In addition to the delay in receiving treatment with Interferon and Ribavirin mentioned above, Luke also experienced difficulties accessing alternative care and support. In fact, Luke had to demand it. It wasn't made available to him. He had to seek it.
- 6.1. Luke went to see Dr. Laffan last Christmas (2017) and told Dr. Laffan what he thought of the treatment he had received. Dr. Laffan finally got Luke sorted with counselling. By this time Luke was 36 and he

had been told of his illness when he was 15. So it took Dr. Laffan 21 years to realise the emotional impact it had had on Luke. It was good counselling in fairness. Luke saw the therapist maybe 8 times. Not a lot, but he certainly benefited from it.

Financial Assistance

7. I cannot say in any detail what financial assistance from Trusts/Funds was received by Luke. What I do know is that he got money from the Skipton Trust at the lower level and that he campaigned to go onto the middle level. I do not really understand this, but I know he had to jump through hoops. I did not really have anything to do with his financial affairs at this time because by then he was an adult.
- 7.1. I can say that from the age of 15, all the while Luke was at home with me, and during the Interferon treatment we received no financial support at all. However, I was paying for Chinese practitioners.

Other Issues

8. I have not taken part in earlier litigation concerning the use of infected blood products or blood, or in other inquiries or investigations, or in campaigning in relation to such matters.
- 8.1. I have been asked if there are any questions I would like to put to the Inquiry team. I would like to put to the Inquiry team the following questions: -
- Why was Luke tested without our knowledge and consent?
 - Why we were never informed that Luke had Hepatitis C?
 - How the consultants could look me in the eye and not tell me [of Luke's infection status]?
 - How a consultant could instruct me on how to give factor 8 without warning me of the potential danger from contamination
 - Why the laboratories were informed of potential contamination from Luke's blood, and I was not?
- 8.2. I found the Consultants and Doctors to be so arrogant. And that is what needs to be challenged, that kind of thinking. That has to be challenged.
- 8.3. In the haemophilia centres you have the Haemophilia Nurse Sisters. I believe they would have been silenced because they would have known. There is no doubt in my mind that the haemophilia sisters were silenced, because they were nurses and they had access to all the children's' notes.
- 8.4. From the time when Luke started to attend the Hammersmith Hospital, which would have been around 1989-90, we had a Haemophilia Sister and she was there for a number of years. We had

lots of contact with her. I have talked to my partner about this. We felt that there was, this conspiracy of silence, that people were drawn into, having to be silenced by this hierarchy of power. I have no proof of that. It is just how it was. I would be interested to know what she has got to say and I wonder whether or not the Inquiry team is going to speak to the Haemophilia Sisters and Nurses who potentially would have been aware.

8.5. A further set of questions I would like to raise are: -

- What did Luke's General Practitioner (GP) know of any of this (because most doctors will copy GPs into their correspondence)?
- Did Luke's GP know that Luke had been infected with Hepatitis C?
- Has Luke's GP got any notes which his supplied medical file do not contain and which informs the GP that Luke had actually been affected?
- Has the GP got any letters that somehow didn't manage to get to us?
- If Luke's GP did not know about any of this, why were the doctors not communicating with the GP and sharing information?

8.6. Our GP doctors were at the Brentford Health Clinic. We just saw any doctor because most of the time we were going to hospital rather than to see our GP. In Luke's medical notes there is a letter dated January 1999, from a Dr of the Brentford Health Clinic (Albany Road, TW8 ONE) referring to Luke's diagnosis with Hepatitis C.

8.7. Dr. Laffan had taught me how to give intravenous injections, knowing that Luke had Hepatitis C. Dr. Laffan showed me how to do it but did not say to be careful because of Luke's infection. The medical notes dated 19th November 1983 show 'mother able to give Factor VIII at home.' It doesn't say in the document who showed me how to do it, but the document says it was the Haematology department who showed me. However, I know that it was Dr. Laffan who showed me how to do it because I remember him demonstrating on a dummy arm. I had no idea my son was sick at this time and they gave me a needle.

Statement of Truth

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

Signed

GRO-C

31st Oct 2018

Dated