

Witness Name: Tracey Gillies

Statement No.: WITN6932065

Exhibits: Nil

Dated: 14/09/2023

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF TRACEY GILLIES**

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I provide this statement on behalf of NHS Lothian in response to the request under Rule 9 of the Inquiry Rules 2006 dated 21 June 2023.

I, Tracey Gillies, will say as follows: -

#### **Section 1: Introduction**

##### **Please set out your name, address, date of birth and professional qualifications**

1. My name is Tracey Gillies, my date of birth is 4 June 1966, and my professional qualifications are MBChB FRCS. My address is NHS Lothian, Waverley Gate, 2-4 Waterloo Place, Edinburgh, EH1 3EG.

##### **Please set out your current role at the Lothian Health Board and your responsibilities in that role.**

2. My current role is as Executive Medical Director with consequent responsibilities and as Responsible Officer for NHS Lothian.

##### **Please set out the position of your organisation in relation to the hospital/other institution criticised by the witnesses (for example "NHS Foundation Trust ('the Trust') operates from Hospital X and Hospital Y (formerly Hospital Z)").**

3. NHS Lothian is responsible for healthcare provision for the population of the Lothian area.

**Section 2: Response to Criticisms by witness W5503**

The criticisms the Board has been asked to respond to are set out at paragraph 12, paragraph 16, paragraph 17 and paragraph 18 of the witness statement of witness W5503 which state:

**Paragraph 12**

George and I feel that giving us information about Steven's infection of hepatitis C was deliberate. They delayed things and made our lives so miserable we were successfully cut out of receiving the real information. The hospital would always say that Steven was just going along with what we wanted, to please us, which was rubbish. He had the right to make his own decision. He knew what he wanted, and George and I always respected what decision Steven made about his own life.

**Paragraph 16**

There was a time when Steven was fifteen years old, and he went to stay with his sister. They were decorating her house and the fumes from the paint hurt his throat causing him to haemorrhage. He went into hospital because he couldn't breathe and he said to them that all he wanted was Factor VII. The hospital refused saying that this was too serious and that he would need Factor VIII. Steven wrote a note to his sister in the ward saying "I think I am going to die". When we arrived at the hospital, both Steven and our daughter were quite distressed. The doctors had gone to Steven two or three times in the night and had asked him to sign a document so he could receive blood products or he was going to die. What he did that night instead of signing, was write a letter which I exhibit as WITN5503002 talking about how he was prepared to die and would rather die than take treatment. Neither George nor I knew about this, it had been entirely played down until we got there. He got through this episode without treatment in the end. It turned out he had developed a haematoma in his throat because he had an irritable throat and it was causing him to continually cough. It pressed on his windpipe and it was restricting his breathing. He was being threatened all night. The letter I exhibit shows what he wanted when he was fifteen.

**Paragraph 17**

We went to court 3 times over this and we would stand up there and explain our position and the worries. The NHS argument was that the products were heat treated, but no one would listen to us saying “We do not want our son to have anything to do with this treatment whatsoever”.

**Paragraph 18**

The fight to try and protect him, it made us ill. It really made us ill. I have a heart problem now, I’ve developed lupus, the stress of everything caused my immune system to attack itself. The attitude from the hospital was always ‘We don’t care about what you and your son want’, it was a horrible feeling.

4. In my role as UK IBI lead for the Board I received the aforementioned Rule 9 Request of 21 June 2023. I identified Professor Christopher Ludlam as the most appropriate people to consider and respond to the criticisms made. He has now done so and his response is set out below, in his own words.

**Response of Professor Christopher Ludlam**

**Background to witness W5503 son’s haemophilia and its management.**

The witness’s son was born 17 September 1973. As there was a family history of severe haemophilia he was investigated by Dr S H Davies in early 1974 and was diagnosed with severe haemophilia A. His parents were Jehovah Witnesses and did not agree to treatment with cryoprecipitate or factor VIII concentrate. Initially acute bleeds were treated at Leith-D Hospital and later at the Royal Hospital for Sick Children in Edinburgh with bed rest, fibrinolytic inhibitor and splints.

At the age of 3, several carious milk teeth needed to be extracted on two separate occasions. This could only safely be carried out with NHS factor VIII concentrate cover. As his parents did not agree to the treatment, his care was taken over by Dr Davies who arranged for him to be treated with factor VIII concentrate. He continued to receive NHS factor VIII concentrate during the 1970s under the care of Dr Davies.

In 1982 he was found to have a high-level factor VIII inhibitor as a result of previous therapy. Treatment of bleeds was therefore not simple, straight forward or as effective as factor VIII

would be in someone without an inhibitor. At this time he required further carious teeth to be extracted and this was accomplished using the combination of FEIBA and factor VIII. During the 1980s and 1990s the patient and his parents' view about treatment options varied. It was not my view that a legal place of safety order should be acquired when he had a severe bleed or required surgery, but this was the wish of his parents. They had to demonstrate to the Jehovah's Witness fraternity that they had not agreed to his treatment with clotting factor concentrates.

When their son became adult he was also reluctant in the 1990s to have factor VIII or FEIBA treatment, although he did agree to the use of, at this time unlicensed and experimental, synthetic recombinant VIIa clotting factor which was under assessment for treating bleeds in those with inhibitors. This therapy appeared to help reduce haemorrhage. Eventually he was able to treat himself at home with VIIa when he experienced a bleed.

## **Response to the Witness statement as set out in the letter of 30 January 2023 from the IBI**

### **Paragraph 1.1**

I could not identify a paragraph 1.1 in the witness statement. Paragraph 1 gives details of the witness and her son. Below is my response to Paragraph 11.

**Paragraph 11** States that the witness was angry about her son's hepatitis C situation and that treatment decisions were taken out of her hands. Reference is also made in 1985 'that there was something wrong with him, during a consultation but we weren't told what it was. We were kept in the dark all the time'

### **Response**

By the time hepatitis C treatment was being offered to her son in 1993 he was an adult and married. In relation to hepatitis C he was seen by Professor Hayes and myself and he was appropriately investigated. (Some of the invasive interventions which would have been offered to other patients were not suitable for her son because of his inhibitor). The medical records demonstrate that he was well informed about the hepatitis and wished to discuss it with his wife (who was also offered a hepatitis C test) before making a decision about whether to accept interferon therapy. Although Professor Hayes recommended interferon therapy at this time her son did not wish to accept this offer for the time being.

I have reviewed the copy of his case notes and cannot identify what the witness thinks she was not told about in 1985.

### **Paragraph 12**

The witness and her husband felt excluded from decisions about his hepatitis C and its potential treatment. It states that 'I always respected what decision Steven made about his own life'.

### **Response**

As mentioned above by the time her son was being offered treatment for hepatitis C he was an adult and made decisions after discussion with his wife. There is no mention in his case notes of my being approached by his parents in relation to hepatitis C and its treatment in the early 1990s and I don't have any recollection of such an approach. I would only have been able to talk to them about their son's situation with his explicit consent.

The witness, however, does appear to accept that medical decisions at this time were appropriate for her son to make.

### **Paragraph 16**

The witness describes her memory of an incident when her son was 15 years old when he presented with a severe bleed in his throat which caused him breathing difficulties. She states that he did not receive any treatment for the bleed. Attached to her statement is an exhibit which she states was written by her son at the time when he was in hospital 'about how he was prepared to die and would rather die than take treatment'. She states that he was asked 'to sign a document so he could receive blood products or he was going to die'.

### **Response**

Although the witness statement indicates that the episode was when her son was 15 years it actually occurred in 1991 when he was 17 years old. He developed a severe retropharyngeal bleed in his throat. This caused him great difficulty in swallowing. A CT scan confirmed the presence of an extensive retropharyngeal haematoma displacing his trachea. Such bleeds can not only prevent swallowing but can press on the trachea and lead to very severe breathing difficulties. He was prepared to accept injections of recombinant VIIa and this therapy initially appeared to reduce the haemorrhage. There was a further bleed into the

haematoma but additional injections of VIIa were effective in inhibiting further bleeding. The haematoma eventually resolved and he was discharged.

I have tried to make out the text in the exhibit. It appears to state that when he was in hospital (and previously) he had a lot of injections and that as he got older he got used to them. He states 'I suffer from severe haemophilia it is a painful disease'. It does not appear to state that he would rather die than receive treatment.

As the witness correctly indicates we were very concerned about this haematoma and its clinical consequences. It is likely that he was reviewed several times during the night by the medical staff (as the witness claims). The case notes record that I saw him and told him about the potential severity of the bleed but he was adamant that he did not want the medically preferred therapy with FEIBA and factor VIII. I cannot find any record of him being asked to sign a form declining treatment with FEIBA and factor VIII. It would have been inappropriate to have asked him to do so. At the time he was under the age of 18 years and if he, and his parents, declined factor VIII and Feiba therapy (if the VIIa had been ineffective), and I viewed this essential to preserve his life (possibly endangered by asphyxiation) I would have sought an emergency Place of Safety Order (as had been done previously).

The copy of the exhibit to the witness statement is difficult to read. It is dated 17 September. It appears to describe the distress of repeated injections (over many years) and that he has suffered a lot of pain. Although the witness claims that the exhibit records that 'he was prepared to die and would rather die than take treatment' I could not see this in the exhibit. Her son was admitted to hospital with the retropharyngeal bleed on 27 May 1991 and discharged 3 days later on 30 May. It therefore seems unlikely that this exhibit dated 17 September was when he was in hospital with this retropharyngeal bleed.

### **Paragraph 17**

This states that his parents went to court 3 times in relation to their son's treatment.

### **Response**

The case notes record that I did not consider it in their son's best interests to have a court 'Place of Safety' order. The parents wished to have the court order to show to the Jehovah's Witnesses that they were not agreeing to his treatment. On one occasion when their son presented with a very severe bleed, in the middle of the night I reviewed him and we had



to obtain an emergency Place of Safety order via the duty emergency social worker and the court before we could treat him.

### **Paragraph 18**

In this the witness reflects on the strain of looking after her son and states the hospital 'don't care about what you and your son want'

### **Response**

I entirely agree that looking after a child with severe haemophilia with an inhibitor is stressful, this being exacerbated by the obligation placed on the family from the Jehovah's Witness community that blood products should not be administered. The non-use of blood products resulted in the witness's son suffering much greater pain and distress from haemophilic bleeds as he was growing up.

I am sorry that she does not consider that we cared about the witness and her son. I and many medical and nursing colleagues in the haemophilia team tried to do our best to help her son in sometime very difficult and challenging medical and social situations. I believe that we provided a high standard of care 24 hours per day over the past 50 years. This I believe would be supported by the detailed narrative in her son's 11 volumes of medical records.

### **Section 3: Other Issues**

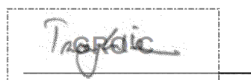
**If you hold evidence you consider may be relevant to the Inquiry's investigation of the matters set out in its Terms of Reference, please insert here.**

5. None.

### **Statement of Truth**

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

Signed



Dated

14/09/2023