

Witness Name: Tracey Gillies
Statement No.: WITN6932056
Exhibits: Nil
Dated: 29/05/2023

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF TRACEY GILLIES

I provide this statement on behalf of NHS Lothian Health Board in response to the request under Rule 9 of the Inquiry Rules 2006 dated 13 September 2022.

I, Tracey Gillies, will say as follows: -

Section 1: Introduction

1. Please set out your name, address, date of birth and professional qualifications

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

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

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

3. 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)”).

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

Section 2: Response to Criticisms by Witness W2111

4. The criticisms I have been asked to address are:

Paragraphs 16 – 19

16. Information about hepatitis C was provided by the Consultant Oncologist at the Western General, Hospital in Edinburgh who was treating Billy. Other than the original discussion where he was told that he had hepatitis C and its impact on his cancer treatment, Billy was given no further information. All further discussions and information given were focused around his cancer treatment. There was no indication of the seriousness of the infection, nor of its potential impact on his life expectancy. The only comment made was that the chemotherapy could activate the dormant infection.

17. Adequate information was not provided. All of the information provided to my brother related to the cancer treatment. The focus was all about treating his cancer first and then deal with the hepatitis C at a later date, unless the hepatitis C flared up. Their view was that if the hepatitis C flared up then the chemotherapy would be halted, the hepatitis C would be treated and then chemotherapy would recommence. At no time was any information given about the possible consequences of the hepatitis C flaring up.

18. Billy had stage 4 liver cancer. It was very aggressive and he was given a very aggressive course of treatment. At that time all of the focus was on treating the cancer. He underwent 21 sessions of chemotherapy in the initial three-week period of treatment. The strength of the treatment was such, the nurses administering the drug, questioned on multiple occasions whether or not he was being given the correct dosage. He reacted badly to the treatment and was admitted to intensive care on 2 occasions, eventually being put into an induced coma to try to allow his organs to rest. He was in isolation during this period, with only my sister in law being allowed to see him. Instead of spending 3 weeks in hospital, he remained there for 4 months, in both intensive care and high dependency units. The whole period for our family and my sister in law in particular, was horrendous. My brother was never given adequate

information on the hepatitis C infection, how it is contracted, how or if it is treatable, the potential consequences of the infection on him, his wife, his life or his livelihood.

19. Information should absolutely have been provided to my brother earlier. It should have been provided when the NHS, its suppliers, and the various UK Governments became aware that they had infected people. It was their responsibility to contact those people who received blood products and/or whole blood transfusions. My brother was diagnosed with liver cancer in 2010, 24 years after he received infected blood. The relevant authorities knew over thirty years previously that people had been given infected blood yet they did nothing. No one from any authority ever contacted Billy to either inform him that he may have been infected or, more importantly, give him the opportunity to be treated for the infection.

5. At paragraphs 16-19 witness W2111 states that her brother was informed that he had hepatitis C as part of a wider discussion about its impact on his cancer treatment, and that adequate information was not provided, or the information being provided relating to the cancer treatment. I am sorry that the witness W2111 feels her brother was not provided with adequate information. In 2010 her brother was diagnosed with high grade diffuse B cell lymphoma at stage 4b. This is a very serious blood tissue disorder and it is therefore likely that the bulk of time spent in communicating with her brother about this diagnosis related to the treatment for this. At paragraph 18 witness W2111 states that her brother began an intensive course of treatment. This treatment was to address the lymphoma, which was present in the liver, in lymph node tissue and in other deposits in the abdomen and pelvis.
6. I am sorry that the seriousness of the diagnosis of widespread and high grade lymphoma meant that the information and advice provided of hepatitis C was necessarily overshadowed.

Paragraphs 22 and 23

22. My family was horrified at the way in which the confirmation of the infection was communicated to Billy and Linda. He had just been told that he had stage 4 liver cancer, not the 'treatable' NHL and then he was told that he had hepatitis C; a fact known but not disclosed to him since 1986, and that he may have infected his wife; the latter delivered as a throw away remark. It was appalling.

23. Given that Billy was never told that he had hepatitis C he was never given any information about the risks of infecting others. The only information given was in 2010 by way of a throw away remark by the same doctor who informed my brother that he had been infected.

7. I am sorry for any shortcomings in the way information was communicated. The disease witness W2111's brother was diagnosed with in 2010 and which was communicated to him and his wife was lymphoma, not hepatocellular carcinoma, and there is no evidence in records I have access to that he was known to have hepatitis C before this.

Paragraphs 33 – 38

33. He was treated in 2010 with chemotherapy for the liver cancer. The liver cancer was declared inactive in 2011 following treatment. He was never able to receive treatment for the hepatitis C as his white blood count never reached the required levels to commence treatment. He was told in 2012 that even without the treatment for the hepatitis C, he had a life expectancy of 10 years, meaning that treatment was not urgent. He was further told, that a new less invasive drug would be made available within a few months, that he would be treated with. He was never offered the new drug.

34. In July 2012 Billy had a 'routine' scan and was told his cancer remained inactive, but that he still could not commence the hepatitis C treatment because his white blood count continued to be too low, and that the risk of infection from the treatment (because of its effect on the immune system) was too high for his body to sustain. In December 2012 he attended a further appointment which included a further scan. He was not given the results of the scan, nor was he contacted by the hospital.

35. In late December his condition deteriorated and my sister in law contacted the hospital for an early appointment for him, which was given to take place at the end of January. She asked for, but was not given, the results of his scan. She was told there had been a mix up because of holidays and that his results would be in the post. In early January my brother was so ill, Linda took him to Dumfries Royal Infirmary which was where his then business was located. He was admitted as an emergency patient.

36. That evening the doctor at ORI after having contacted the WGI in Edinburgh for Billy's medical records, told them that the scan taken in December had shown that the

cancer had returned, had spread and was inoperable. They sent him home to die. On return to Edinburgh, after great effort, he was given an appointment to see a Consultant Oncologist who confirmed his condition. They apologised for the way in which they had been treated and told him nothing further could be done. My brother asked to be treated with a lifesaving drug. Sorafenib, which was not available to NHS Scotland patients, but which was available in England.

37. He and our family, offered to pay for the treatment as we knew it had proven success rates. He was told that his condition was too far advanced, so his request was denied. He was also told that had his condition been identified four months earlier he would have been eligible for treatment. When we asked why he was given scans at six monthly intervals and not three months, which would have identified the cancer's return, we were told that it was standard procedure. Again, my brother was denied potential lifesaving treatment because of NHS 'protocol'.

38. My brother was denied access to both Sorafenib, for his cancer and Ribavirin for the hepatitis C, both of which are proven drugs.

8. I am provided with information by Dr Bathgate and Mr Powell regarding the care of the witness W2111's brother. Dr Bathgate has commented on the delay in receiving the MRI results taken in December 2012 which showed a very significant change in the appearance of the liver and showed extensive hepatocellular carcinoma, with no evidence of recurrence of lymphoma. It is not possible to determine why this result was not returned to Dr Bathgate other than by speculation. Dr Bathgate apologised for this delay in explaining the results when he saw the witness W2111's brother on 22nd January 2013 after his brief admission in Dumfries (DGRI). The results of the December MRI were highlighted to the witness W2111's brother when he was an inpatient in DGRI and staff there contacted Dr Bathgate to discuss the result of the December 2012 MRI scan.

9. The use of Sorafenib: the view from the oncology team was that the use of this medicine would have been more likely to shorten the life of the witness's brother and so it was not recommended. This was explained to the witness's brother and his wife when they saw the oncologist on 31st January 2013.

10. Mr Powell and Dr Bathgate are both clear that the delay in explaining the MRI results to the witness W2111's brother in December 2012 was very regrettable and should not have happened, but did not impact on any treatment options no longer being available.

11. At paragraphs 36, 37 and 38 the witness W2111 states that her brother was denied access to medicines, but the health records considered indicate that neither medicine mentioned could be used without significant adverse impact on her brother's deteriorating health.

Section 3: Other Issues

12. 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.

None.

Statement of Truth

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

Signed

GRO-C

Dated

29/05/2023