Witness Name: Wendy STUBBS
Statement No: WITN00873008
Exhibits: WITN00873009 –
WITN00873017
Dated:

INFECTED BLOOD INQUIRY

SECOND SUPPLEMENTARY STATEMENT OF WENDY STUBBS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated11 March 2019.

I, WENDY STUBBS, will say as follows: -

Section 1: Introduction

1. My name is Wendy Stubbs. My date of birth and my address are known to the Inquiry.

2. I wish to provide additional evidence to the Inquiry updating information relating to the ever-changing condition of my husband Stephen, along with my struggles to obtain additional financial support.

Section 2: Update on Stephens Condition

3. In my previous statement to the Inquiry dated 11 September 2019, I briefly described some of Stephen's symptoms and why I believe he may have contracted vCJD through contaminated blood products. I had first noticed a change in Stephen's behaviour in about 2012 after his failed Hepatitis C treatment but it really started to cause great concern in 2016. He developed some bizarre behaviours, for example, he would only eat with one particular spoon and all the mugs hanging in the kitchen had to face the same way, both things which had never bothered him before. He started grinding his teeth and his eyes would flicker and he developed involuntary muscle spasms in his arms. I was a nurse for over 30 years and have experience of both early onset dementia and dementia in the elderly and I felt that Stephen's behaviour was most unusual.

4. Since my previous statement, Stephen's condition has deteriorated to the extent that I was left with no alternative but to place him in a nursing home on the 20th May 2020. Stephen now requires 24-hour care and I was no longer able to provide him with the care he needs on my own.

5. My daughter usually accompanies me when I visit Stephen as I find his deteriorating condition very distressing. It now takes him a few minutes to even recognise me and even then, it is only a slight flicker of recognition. He can no longer walk, talk, feed himself or use the toilet and it is terrible to see. Stephen is still alive but he may as well not be.

6. I see a counsellor once a week which I am finding helpful. also receive support from Sam at the Hep C Trust and Jessica from the Haemophilia Society. I am also in constantly in contact with Sir Brian Langstaff. Most of the time I hate my life and wish this would all just go away. I feel angry that all the plans that Stephen and I had for our retirement have come to nothing and I am essentially on my own

7. Although Stephen has never been refused treatment as far as I am aware, I have had to fight to arrange for him to have his regular haemophilia assessment. His last assessment was done in 2019. It is important that he has this assessment as it may establish that his cirrhosis has developed to the point where I may be able to apply on Stephen's behalf for the hepatitis C Stage 2 payment which would make a huge difference to our lives. I feel that I constantly have to fight for Stephen's treatment and to get anything done is a battle.

8. Until a few years, I was not aware that Stephen was considered to be 'at risk of vCJD'. I had never had a conversation with any of his medical practitioners about this despite it being highlighted in his medical file [WITN00873009]. However, I did find a document amongst Stephen's medical records which indicates that Stephen was told of the risk of vCJD in January 2005 by his haematologist, Dr Parapia. [WITN00873010] Stephen never mentioned this possible risk to me. I was also surprised to find a document with an entry dated 14 September 2010 which states "At risk of variant Creutzfeldt-Jakob disease (finding) (Confirmed) – presented on 14/09/2010". [WITN00873011]. I don't know what this means nor has it ever been explained to me.

9. Although Stephen's medical records were marked that he was 'at risk of vCJD' I do not recall ever having received any notifications or updates from either his medical practitioners or from the vCJD section at Public Health England (now the UK Health Security Agency) which I believe we should have.

10. As recently as 2018, and despite the fact that Stephen's file is endorsed as 'at risk for vCJD', nobody appears to have explored the possibility that Stephen's memory loss and subsequent dementia diagnosis could in fact be as a result of vCJD, not because of his previous (unsuccessful) hepatitis C treatment. [WITN00873012].

11. On the 18th April 2018 Stephen was examined by a Consultant Neurologist, Dr Busby because of his memory loss and disorientation. No mention is made in this letter to Stephen being at risk of vCJD and I can only assume that this detail was left off the referral letter from the haematology department. I include Dr Busby's report as [WITN00873013] as he sets out Stephen's symptoms in some detail. I also include a letter from Stephen's haematology consultant, Mr Samuel Ackroyd where he records that I raised the possibility of CJD being the cause of Stephen's dementia or whether it could be related to the Hep C or Hep C treatment. [WITN00873014]

Section 3: Update on Financial Impact and Assistance

12. I wish to update my first supplementary statement where I described the fact that Stephen had initially been refused payment of the Special Category Mechanism (SCM) which he was invited to apply for in late 2017. [WITN00873015]

13. In the response from EIBSS dated 12 April 2018, Stephen's application was refused on the basis that the supporting medical information we supplied did not provide sufficient evidence that his Hepatitis C infection and/or his treatment was having a substantial and long-term impact on his ability to carry out daily activities. Furthermore, the EIBSS assessors and his medical practitioner were unable to conclude that Stephen's conditions were attributable to his Hepatitis C infection or treatment. [WITN00873016]

14. With the support of Mr Ackroyd, I reapplied on Stephen's behalf and he has now been granted the SCM payment. It is also a great help that the need to reapply every year has also been done away with. [WITN00873017]

15. In my first statement, I mentioned that Stephen had been granted the hepatitis C Stage 1 payment of £20 000. In July 2021, EIBSS announced that all current beneficiaries of the Scheme that had received the hepatitis C Stage 1 lump sum would receive an additional payment of £30 000 bringing the Stage 1 payment in line with the Scottish Infected Blood Support Scheme. We received this payment on 27 July 2021.

16. As I have mentioned above, Stephen had to be placed in a nursing home in early 2020 as I was no longer able to cope with the care he needs on my own. The nursing home costs around £600 per week, of which I have to contribute £124. The balance is paid by the local authority (£250) and Stephen's employment support allowance (£228).

17. Due to my own ill health, I am no longer able to work and receive an amount of £630 per week from my employment support allowance and universal credit. It is from this amount that I have to contribute to Stephen's care.

Section 4: The vCJD Trust

18. Prior to my meeting with the Inquiry team, I had never heard of the vCJD Trust before. I believe that I should have been advised of the Trust's existence as I would definitely have got in touch with them. I have now made contact with Johnathan from the vCJD Surveillance Unit in Edinburgh who have explored Stephen's last test results. They were not aware that he had been given contaminated blood products in the past so I have provided them with the batch numbers of the products Stephen received as well as details of his symptoms. Johnathan expressed his shock that Stephen has not been under their care, support or radar. We made an arrangement for Stephen to be assessed by the Surveillance Unit at his nursing home on the 9th March 2022.

Section 5: Update on Stephen's Assessment

19. On Wednesday, 9 March 2022 Stephen was assessed by two doctors from the Edinburgh CJD Surveillance Unit, Dr Jonathan Tan and Consultant Neurologist Dr Suvanker Pal at his care home in Bradford.

20. Due to the limited time that they had to spend with `Stephen and I, they kept their questions very structured in order to cover as much of Stephen's history as possible. The types of questions that they asked me were:

    i. When did I notice a change in Stephen's behaviour and what were some of the symptoms that concerned me?
    ii. Had Stephen suffered from dizzy spells, balance problems, had falls and a change of gait?
    iii. Did he have blurred vision, slurred speech, was he seeing or hearing things and did he have any pain?
    iv. What was his mood, his facial expressions, his libido like, was he anxious or lethargic and what was his appetite or alcohol consumption?
    v. When did we approach his GP and when were we referred to Mr Busby and Mr Ackroyd? What support had we received from them?

21. They were very interested in the detailed evidence that I have of Stephen having received implicated blood products. I have the batch numbers and hand written batch numbers all referring to what products had been administered to Stephen.

22. I was asked to provide consent for blood to be taken from Stephen for gene analysis, CJD screening and various other tests that they wish to run. I also agreed for Stephen to have a cat scan which I believe is the least invasive way to indicate possible CJD. It was suggested that

Stephen be transferred to the Prion Unit in London but I felt that this would be too much for Stephen to deal with in his condition. I also refused the suggestion that Stephen undergo a lumbar puncture as I feel that this would be beyond cruel for him to endure. Stephen remained relaxed throughout the discussion.

23. The physical examination of Stephen was very specific and was to establish and note his involuntary muscle spasms, his muscle tone and his reaction. When the neurologist, Dr Pal, tapped his chin, Stephen pouted his mouth. I commented that he does this often and Dr Pal explained to me that this was a sign of an advanced brain injury.

24. At one point during the examination, Stephen was shaking dreadfully, with tremors and flinching. These were noted as being symptoms of Parkinson's and Motor Neuron Disease, both of which had apparently been ruled in the previous tests conducted by Dr Mark Busby.

25. Unfortunately, Stephen had had a bad fall the day before the assessment and his face was badly bruised and he had a cut which was closed with steri-strip. He falls regularly now if he is not supervised. The doctors wanted Stephen to stand which he was unable to do without help. He was very unsteady and was shaking profusely. Stephen found this very traumatic and as soon as he could, he sat back on his bed very quickly. Without my help, he was unable to shuffle back into a sitting position – he was as stiff as a board and very difficult to move.

26. At the end of the assessment, Dr Pal and Dr Tam told me that there was no cure or treatment for Stephen's condition, which of course I already knew. They explained that is also the possibility of not being able to confirm a vCJD diagnosis until after Stephen's death. They have provided me with a post mortem consent form to read and Dr Tan has said that he would go through it with me another day as they felt that I had been through enough for one day.

27. Dr Pal has told me that he would inform the Prion Unit of Stephen's clinical condition. He has also undertaken to contact the vCJD Trust to establish what is required to support a claim for support or compensation considering Stephen is still alive and vCJD has not been confirmed by way of a post mortem.

28. During Stephen's assessment, I did get upset. I am beyond worn out with this situation. It is death row for us, just waiting …I live on benefits and a very small pension. I may have to sell my house if I don't get financial security. The whole situation makes me feel so bitterly angry because I feel that Stephen is only in this condition because of the cocktail of poison that he was given.

Statement of Truth

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

Signed **GRO-C**

Dated 5|4|22.