Witness Name: SUSAN EDWARDS
Statement No: WITN4706001
Exhibits: 0
Dated: November 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUSAN EDWARDS

I, SUSAN EDWARDS, will say as follows:-

Section 1. Introduction

1. My name is Susan Edwards. I was born on GRO-C 1960 and I live at GRO-C GRO-C, GRO-C Cheshire GRO-C with my husband, Robert.

2. My husband, Robert Malcolm Edwards (born on GRO-C 1958), is infected with the Hepatitis C Virus (HCV) from a transfusion of contaminated blood at the Wrexham Maelor Hospital (WMH) in 1981 or the RAF Hospital, Ely (Ely) in 1983. Without knowing it, he has been infected with HCV for almost 40 years and was only informed (last year) in 2019.

3. This witness statement has been prepared without the benefit of access to my husband's full medical records. Robert has provided his own Witness Statement to the Inquiry (WITN4705001). This Statement should be read in conjunction with my husband's Statement.

Section 2. How Affected

4. Robert (Bob) had three operations in total. He had two pyleoplasties at WMH in1981. Both failed. His left kidney was removed (nephrectomy) at Ely in 1983.

5. Bob was transfused with three units of blood at Ely on 12th May 1983 with the following batch numbers: 6301 825, 6311 431 and 6311 440. The notes he has pertaining to the transfusion on 12th May 1983 indicate that he was given a previous transfusion(s), likely given the nature of the two previous pyleoplasties undertaken in 1981. WMH have destroyed the records for this period.

6. Whilst in the RAF, Bob received a letter from the blood service after donating blood on his 35th birthday. The letter informed him that his blood had been analysed as having NANB hepatitis antibodies and, as such, he was an unsuitable as a future donor. He did not understand the significance of the letter and, after speaking to his Medical Officer, he was left believing that he was just a 'carrier'.

7. Bob and I met in 1999. We lived together for ten years before we married in 2010. Within a short period of us meeting, Bob told me all about the life he had had in the RAF. He also mentioned to me that he was a carrier of HCV and that he didn't need treatment (he believed he did not have HCV). That was the end of the conversation. There was nothing more to say. After receiving the letter from the blood service and being reassured by his Medical Officer, Bob carried on with his life. He had no follow-up information or advice about his NANB Hepatitis/HCV status and there is a huge amount of ignorance around HCV even now. Bob has told various GPs that he is an HCV carrier ahead of a consultation in case it is something they need to know. No-one has ever corrected him and said that there is no such thing as a carrier of HCV.

8. I first noticed that something was wrong with Bob after the 2018 Christmas period. He wasn't himself. His stomach was a lot bigger and he started to go downhill from there. He looked like he was gaining weight (and looked as though he was 9 months pregnant by the time he saw his GP in April 2020) and he felt lethargic and run down. On 1st April 2019 Bob became seriously unwell over the course of a day. We had gone out for a drive that day and after stopping for lunch, Bob asked that we go straight home. He said he felt 'awful' and lay on the sofa. He didn't wake up properly until Monday morning. After that, he agreed to see our GP immediately presenting with ascites, the GP arranged for a CT scan straight away. Bob was subsequently told that he had cirrhosis and liver failure by the GP and we arranged to see a liver specialist at a private appointment at the Nuffield Hospital in Chester. The specialist informed us that there is no such thing as a 'carrier' of HCV. He was advised to have a HCV blood test which was arranged and showed a live viral load. Those results came through in the summer of 2019 and I immediately also arranged a HCV test for me which was negative.

9. Since learning that the virus is active, Bob had to go away and research it, it's effects and prognosis and he spent 7 grueling months digging through archived military material looking for the information missing from his GP and NHS hospital records. The exertion took its toll on him and his already depleted energy levels. He was wiped out and I was really worried about him.

10. Through his research, Bob established that he first tested positive for HCV in 1992. HCV appears to be an issue amongst RAF and Army personnel (with a collation of data recorded in the archived material), the probable source of the infection appears to be blood transfused at Ely and/or other military hospitals. Bob had a niche role in the RAF in counter espionage. He was exceptionally important and it would not have been conducive to remove him from operations for tests and treatment. His medical notes show he should have been referred for Interferon treatment and a biopsy – this did not happen and he was not told

about this being a requirement. He left the RAF in 1998 having been examined and wrongly deemed medically fit for discharge. It is, in fact, noted in Bob's exit medical record that he had an enlarged liver and spider naevi at that time, suggesting liver disease and esophageal varices. Bob should have been told about the problem, given a biopsy and put on to Interferon treatment.

Section 3. Other Infections

11. I do not believe that Bob is infected with anything other than HCV.

Section 4. Consent

12. Bob was not informed of the risk of contamination associated with having the blood transfusion(s) before or after his surgeries.

Section 5. Impact of the Infection

13. Bob has cirrhosis and end stage liver failure. He has varices, portal hypertension, hepatocellular cancer of the liver (two lesions diagnosed in February 2020), anaemia, hepatorenal syndrome and ascites. From time to time he also suffers with encephalopathy with toxins building up in his bowel as a result of liver failure.

14. Prior to 2019, Bob was super fit, capable of doing 100 planks, sit ups and press ups daily (getting rebuked by me for starting them at 6.30 am). He would also lift weights and had developed good muscle tone (he can't turn the lid on a marmalade jar now). Bob was a keen and talented photographer and would lug heavy camera equipment around with him. We had an active life together. We have four lively dogs and walked them daily. We went out to dog events and country fayres. Since April 2019, when Bob became very ill very quickly, he has needed constant care and support. His liver has ceased to compensate and he

has been unable to work, exercise or walk very far. The illness has changed both of our lives beyond recognition. It has meant that I have had to change my own legal consulting business to a training business so I can do this around my caring duties which are in excess of 40 hours per week day and night. Last week I did over 70 hours care.

15. The first (12 week) round of HCV treatment (licensed through the Aintree Hospital) failed. He has just completed another round of HCV treatment this time it lasted 6 months. It was grueling for Bob and all he did was sleep. He had weekly blood tests and was clear of the virus for just one week. Once the liver has become fibrotic through cirrhosis damage, the treatment is less effective and less likely to succeed.

16. Bob was referred to Professor Neuberger and the transplant team at the Queen Elizabeth Hospital (QEH) in Birmingham as a liver transplant was thought of as being Bob's only chance. We were informed by Professor Neuberger that he considered Bob to be a challenging candidate regardless of him being able to successfully clear the virus. He has one kidney and a transplant would place him at significant risk. The shortage of donors anyway results in a distinct lack of gold standard livers. Should a liver become available, it could well be from an older donor and/or be damaged. If that wasn't hard enough to hear, Dr Neurberger told us that it was almost inevitable that Bob would go on to develop hepatocellular cancer of the liver. We discussed this at length with our GP, our local NHS consultant and Bob decided the risks were too great.

17. At one time Bob was continually jaundiced. Encephalopathy became a huge problem last year for Bob. He wasn't himself and had uncharacteristically become confused and belligerent. Before his medication brought it under control, I feared the change in him was going to be a permanent state. When admitted to our local hospital, the Countess of Chester Hospital (CCH), Bob was treated by the staff as though his failing liver was self-inflected through alcohol

abuse. That was pretty much their default position every time Bob needed tests or treatment there. Notwithstanding the HCV diagnosis, they were cynical about Bob being culpable for his very poor health. Dr Neurberger had questioned Bob about his alcohol intake levels. Bob has kept himself physically fit and led a clean lifestyle with a modest alcohol intake. Dr Neurberger was very clear that given the length of time Bob has been infected with HCV, this would have happened to Bob any way.

18. Bob and I had successful businesses and were financially secure at the back end of 2018. Bob has had no alternative but to wind down and close his business as a food photographer and blogger. My own business has changed beyond recognition and is now almost non-existent because of the round the clock care Bob now needs. At one time we had only Bob's RAF pension and we were reliant upon my borrowing to get by. It took us some time before Bob could identify the evidence of a transfusion(s) we needed to find in order to satisfy the EIBSS that Bob was entitled to make a claim. I had to take out personal loans to live, copy with the additional expenses and be able to pay a specialist chauffeur to transport us (with Bob's wheelchair) to and from the QEH for appointments. For me to drive him that far and provide him with the care he needs during the journey was impossible. Bob needs help with everything to include waking him and/or prompting him to take his medication three times daily, take fluids, ensure he has moved his bowels (he needs to have a bowel motion two or three times daily to regulate his encephalopathy) and eat.

19. There is not one area of our lives left unchanged. We used to be able to pretty much suit ourselves in how we went about our daily lives. Bob used to love to cook and did all the cooking. He has tried and has ended up on the kitchen floor with exhaustion. We can't walk the dogs together or drive anywhere, we can't go on holiday, out for meals or entertain friends. Bob can no longer hold a conversation and forgets things which he is embarrassed by. Bob has always been mentally sharp and we always complimented each other in the way we

used to converse together. I miss our banter. Bob feels cold all the time. He can't regulate his body temperature and he needs the temperature up very high in the bedroom and bathroom when he showers. I now need to sleep in a separate bedroom to Bob to try to get enough sleep to get through each day. Bob can get restless at night and likes to have the TV on for company a couple of hours in the early hours before he drifts off to sleep again. I need to get up during the night to monitor him as well as the regular care he needs throughout the day.

20. Bob was again admitted to hospital on an emergency basis this year having been taken off a diuretic drug and unknowingly contracted sepsis through the build - up of ascites fluid. Having sepsis exacerbated Bob's encephalopathy. He was in a terrible state and oblivious to everything going on around him when the ambulance medics arrived, having collapsed trying to use the bathroom. He was drifting between life and death on his admission to hospital.

21. I try to ensure that every day is as a good a day as possible for Bob. I try very hard not to ever become impatient with him as the encephalopathy means he can be argumentative and unreasonable at times. We make the best of everything as much as we can. We are still able to laugh together and I want Bob to be as happy as he can be. I do not want to have any regrets.

Section 6. Treatment/care/support

22. Bob has just completed a second round of HCV treatment and will now have to wait three months for a further viral load test to see if the virus has cleared so will not know until February 2021.

Section 7. Financial Assistance

23. Bob has managed to uncover enough medical evidence to satisfy the EIBSS that he was the recipient of blood transfusion(s) and have even identified the batch numbers of the units of blood I had in Ely in 1983. He needed to do this to be able to claim the Stage 1 ex gratia EIBSS payment before the additional Stage 2 payment. NHS hospital records are destroyed 7 to 10 years from patient discharge and the WMH no longer have Bob's inpatient records from 1981. The chances of others equally able to easily establish that they were transfused in the 1980s in the absence of NHS records is virtually nil.

Anonymity, disclosure and redaction

24. I am not seeking anonymity and I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed...... GRO-C ....

Dated....11...11....2020..........................