

Witness Name: ROBERT MALCOLM EDWARDS

Statement No: WITN4705001

Exhibits: 0

Dated: October 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROBERT MALCOLM EDWARDS

I, ROBERT MALCOLM EDWARDS, will say as follows:-

Section 1. Introduction

1. My name is Robert Malcolm Edwards. I was born on GRO-C 1958 and I live at GRO-C Cheshire GRO-C with my wife, Susan (Sue).
2. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

3. I am 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 me knowing it, I have been infected with HCV for almost 40 years. I was only informed that I had HCV (last year) in 2019.

4. I had three operations in total. I had two pyleoplasties at WMH in 1981. Both failed. My left kidney was removed (nephrectomy) at Ely in 1983.
5. I 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.
6. The notes I have pertaining to the transfusion on 12th May 1983 indicate that I have been given a previous transfusion(s) which I do not remember but I believe likely given the nature of the two previous pyleoplasties undertaken in 1981. WMH have destroyed the records for this period.
7. Prior to April 2019, I was (I thought) fit and well. I had had the occasional bout of gout and the occasional, unexpected and out of the blue 48 hour fever. I used to be in the military (the RAF) and, up until the beginning of last year, I had maintained a good fitness regime and generally maintained a healthy diet.
8. I had donated blood whilst in the RAF on my 35th birthday. I subsequently remember receiving a letter from the blood service (I no longer have that letter) informing me that my blood had been analysed/identified as having NANB hepatitis antibodies and informing me not to bother donating again (or words to that effect). I did not understand the significance of the letter but I remember showing it to my Medical Officer the next day and asking him 'what do you know about hepatitis?' He said 'very little'. He confirmed what I thought to the case, that I 'should be fine' as it sounded like I was just a 'carrier'. Not a huge amount of information was available at that time and life for me went on as normal.
9. I had no follow up contact from anyone with help, information or advice about NANB Hepatitis/HCV after receiving the letter.

10. I became aware that something was wrong after the 2018 Christmas period. Sue and I noticed that my stomach was a lot bigger. I was never previously going to develop a six-pack, because of scar tissue and surgical disruption but I used to have something akin to a four-pack. At first I put the large stomach down to relaxing and overindulging over Christmas but ultimately (in or around April) I went to visit my GP, presenting with what I queried might be ascites. I had the presence of mind to have a photo with me taken at my 60th Birthday 9 months previously showing how lean and toned I was then because, after a physical examination by the GP, I was told that there was little evidence of it (ascites). I was going to be referred to a NHS specialist but that would have involved a long wait and I opted to have a private examination at the Nuffield Hospital in Chester instead.

11. At my hospital appointment at the Nuffield, I was told that I have HCV and that my liver is no longer compensating for the damage. I was told that there is no such thing as a 'carrier' of HCV in as much as you either have it or you don't and I have had it for a very long time. There was no record of me having HCV in my GP records. Since being informed that I have HCV, I have been pro-active in researching the virus, its effects and prognosis and have spent 7 months digging through archived military material looking for the details of how I was infected with HCV, missing from my GP and NHS hospital records. When joining my current practice around Jan 2000, my GP was not computer literate and I added my HCV 'carrier' status to my own record at the surgery.

Section 3. Other Infections

12. I do not believe that I have been infected with anything other than HCV.

Section 4. Consent

13. Some form of nebulous risk may have been outlined to me before the pleuroplasties in 1981 but I cannot specifically recall it. A career in the military always involves living with some form of risk. I had surgery on an emergency basis for the nephrectomy in 1983. It was obvious that I had had a blood transfusion when I came round after the operation as there was a unit of pure blood hanging over my bed.

14. I was told before the nephrectomy that 'any surgery includes risk'. There was no reason for me to believe afterwards that I might have been infected with HCV. Through my research, I have established that I first tested positive for HCV in 1992.

Section 5. Impact of the Infection

15. My health has plummeted since April of last year. At one time I was continually jaundiced and I am no longer able to work, exercise or walk very far. I have no energy. The medical research I undertook over 7 months really took its toll on me. Working daily on the medical research for just 20 minutes or so would result in me needing to sleep for something like two hours.

16. I have cirrhosis and end stage liver failure. I have varices, portal hypertension, hepatocellular cancer of the liver (two lesions diagnosed in February 2020), anaemia, hepatorenal syndrome and ascites. From time to time I also suffer with encephalopathy as a result of toxins building up in my bowel as a result of liver failure.

17. I have just completed a second round of HCV treatment. I 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. The first (12 week) round of HCV treatment failed. I had weekly blood tests. I was clear of the virus for one week but it emerged from

the deep tissue (probably the liver) it had settled in over such a long time the very next week. They are only ever able to test what is in the blood stream.

18. I now suffer with brain fog. I am extremely lethargic and cannot concentrate. I have the concentration span of gnat and will invariably forget what I have said at the beginning of a sentence before I have time to finish it. I am really woolly and indecisive. I never previously had that problem. Fatigue is a serious issue for me. I am wacked just climbing the stairs at home. As a result I avoid going downstairs knowing full well that I will need to come back up. Sue has to provide me with constant care and support. I told Sue that I would make my own breakfast the other morning. It was a simple sausage and egg sandwich. I lack the stamina to stand in the kitchen and was too tired to eat it after making it.

19. Since leaving the military I have worked as a photographer/videographer. I used to think nothing of journeying into distant unfamiliar areas, carrying and setting up equipment to include cameras, tripods, extension cables and the like, doing a full day's work and then dismantling all my equipment, loading up and travelling home. I have taken photographs since the age of 15. Photography is not just a job for me but part of my make-up. I have been teaching my granddaughter photography but meeting up with her and demonstrating in the field techniques is not possible. The tuition and guidance takes place over email.

20. Cooking is another love of mine. Over the past 20 years I have done 98% of the cooking in the household. I must have around 120 books about food (all of which I have read). My palate is shot now and I do not bother. I cannot focus on the task and enjoy the end result. I can no longer do any of the things I love and my brain doesn't work properly. People think boredom is trivial it is not. My life now revolves around sleeping and crap TV.

21. The mental strain I am under is huge. It is a lot to contend with. I have not had the diagnosis but I think I am borderline depressed. I do not harbour feelings of

anger (although I did for a short time). I have managed to uncover enough medical evidence to satisfy the EIBSS that I 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. When I did all that research, Sue was very worried for me. It wasn't easy and I can now concur with Sue that I had become obsessed in getting to the truth. I am really upset for people like me battling the system and trying to legitimately claim for serious long term illnesses after discovering that they were infected with viruses through contaminated blood decades earlier.

Section 6. Treatment/care/support

22. Treatment, care and support for me has come late in the day. My first attempt at clearing HCV failed.

Section 7. Financial Assistance

23. Whilst I was able to claim the Stage 2 ex gratia payment through EIBSS without too much difficulty, to try to claim the Stage 1 payment was very difficult. I have ascertained that NHS hospital records are destroyed 7 to 10 years from patient discharge and the WMH have long since destroyed my inpatient records from 1981. Very many others infected around the same time as me are likely to be dead now and the likelihood of those still alive successfully making any form of link between transfusion and infection in the absence of their NHS records is virtually nil. I was upset and frustrated at the ignorance of the EIBSS processing claims as to how it all works. I am now in receipt of a Stage 1 and 2 payment.

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. 2. 11. 2020