

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1722002

Exhibits: 0

Dated: AUGUST 2019

INFECTED BLOOD INQUIRY

---

SECOND WRITTEN STATEMENT OF GRO-B

---

I, GRO-B will say as follows:-

Section 1: Introduction

1. My name is GRO-B. My date of birth is GRO-B and I live at GRO-B  
GRO-B with my husband, GRO-B: H  
H
2. This is my Second Statement. It should be read in conjunction with my First Statement given to the Inquiry (Witness Number WITN1722001) on 28<sup>th</sup> November 2018. Since making my First Statement, H has been diagnosed with liver cancer.
3. H has given a Statement to the Inquiry (Witness Number GRO-B) on  
GRO-B

**Section 2: How Affected**

4. [H] became co-infected with HIV and Hepatitis C as a result of receiving contaminated blood products, Factor VIII (FVIII).
5. [H] was told of his HIV diagnosis in August 1985 (we had by then met and formed a relationship) and was then told that he had Hepatitis C some time between 1989 and 1992. He attends the Oxford Haemophilia Centre at the Churchill Hospital, Oxford and it was there he was told that he was HIV positive and later, Hepatitis C positive. We married in [GRO-B]

**Section 3: Other Infections**

6. [H] has also received notification that he is at risk of vCJD.

**Section 4: Consent**

7. [H] had no prior knowledge of being tested for HIV and Hepatitis C.

**Section 5: Impact**

8. As a direct result of the infections [H] has succumbed to a wide range of very serious health issues, cascading into further health complications. Moreover, [H] had a brain haemorrhage on 19<sup>th</sup> September 2007 resulting in partial paralysis to the right side of his body. To live with [H]'s infections, has been like living under a continual 'black cloud' of uncertainty. Every time [H] has been seriously unwell, I have thought 'is it now? Is this the end?'
9. [H] was hospitalised for 4 days in 2001 with severe internal bleeding/haemorrhaged varices identified as being caused by liver disease. He

cleared HCV in 2003 after treatment with Ribavirin and Pegylated Interferon but not before contracting sepsis which was almost fatal.

10. In October 2018 [H] had an ultrasound scan. It was suggested to us by [H]'s Consultant, Dr Curry, as something being offered to *all* patients as "a good idea". His last ultrasound scan to review his liver took place as long ago as 2003. The Radiographer conducting the ultrasound scan in October was very reassuring. He said that, whilst [H] had liver cirrhosis, there were "no changes" and everything "looks fine to me". We later took a phone call from Dr Curry confirming all was well with the results of the scan.

11. [H] attends the Haemophilia Centre for routine appointments at 6 monthly intervals. At the appointment in mid March of this year (2019), Dr Shapero told us that they needed a word about [H]'s liver and that they had *looked again* at the ultrasound. I asked "Why?", "What brought that on?" and "but the ultrasound was fine?" on several occasions but did not receive an answer.

12. We were told that the next step was for a (specific) blood test to be undertaken. If the reading was at a raised level it could indicate cancer. As a patient with a high risk of developing cancer I had erroneously assumed that the blood test would have been ordered for [H] along side the bloods taken at his routine appointments. I do not think that to be an unreasonable expectation.

13. The blood test was duly undertaken and we were told that we would hear from them in the next couple of days. When I was contacted by Dr Shapero she told me that the vials of blood taken had been mixed up and that a further blood sample would be taken, through our GP. More time passed by and we heard "sorry the blood levels were higher than we expected, we *are* worried". We were then told that [H] would be sent an appointment for a CT scan within two weeks.

14. The CT scan took place in April and we were told by the Nurse that there was no sign of cancer but that the Hepatologist wanted an MRI because "cancer can hide". I commented to the Nurse that the MRI should have been done in the first place and we were told "No, the NHS does it like this: 1. Bloods, 2. CT scan and 3. MRI." The Easter weekend intervened and more time lost before the MRI scan, which took place on 2<sup>nd</sup> May. After the MRI we were told that [H] has a 2 cm tumour on his liver. We are absolutely devastated.
15. In terms of treatment, five heavy blasts of sabr radiotherapy was the recommendation of the Oncologist. It was the only realistic option available. Given [H]'s haemophilia, surgery is quite rightly out of the question.
16. On 10<sup>th</sup> June [H] had to undergo a compression technique procedure to pinpoint the location of the tumour in relation to his vital organs. The procedure is in itself dangerous for haemophiliacs as intense pressure is placed upon the abdomen, pushing down and jamming the intestines. I was fraught sitting waiting for two hours during the procedure. [H] emerged white and in some discomfort. He was badly bruised on the left and the right side of his abdomen with a slight bruising in the middle of his tummy. I could only think that they had exerted too much pressure when trying to keep his intestines in place for the CT scan.
17. We then had to wait two and a half weeks to start the first of the sabr treatment but after the first, [H] was experiencing severe discomfort and restriction on eating and drinking and was admitted to the JR Hospital for an endoscopy. This revealed severe inflammation and swelling due to severe acid reflux. Omeprazole was given to relieve the symptoms which has continued to do so. We were both very worried thinking there was an added complication to [H]'s initial diagnosis. We have been in a state of limbo, waiting for treatment and terrified that the treatment will result in [H] having a massive, fatal internal bleed. It felt to me like the shutters were down and no-one wanted to speak to us.



18. [H] and I attended the hospital for [H]'s first blast of radiotherapy on Monday 21<sup>st</sup> July and one dose of radiotherapy was given. The next appointment was Wednesday 23<sup>rd</sup> July. [H] was called in at 4.50 pm and was out again at 5.35 pm. The Radiotherapist came into the room and told me that the image of [H]'s liver was not sharp enough for a clear shot. We were anxious to leave as our transport had arrived (I always have to arrange specialist hospital transport) but the Oncologist arrived and explained that radiotherapy was no longer an option as they were worried that they would perforate [H]'s bowel. There are no treatment options now left for [H]

19. [H] and I have been living in a heightened state of stress and anxiety since March. I have been unable to sleep and have barely been able to eat. I struggle to function in undertaking day to day tasks and the garden I love has been neglected. I have never seen [H] so worried. We have been through hell and it is not over yet. The Oncologist has been kind and the hospital staff have now taken on board the importance of communication to us. However, we now need time and space to come to calm ourselves ahead of the inevitable. We are not due to return for our next appointment until 23<sup>rd</sup> September.

20. In summary, I cannot believe the nonchalance and incompetence of the medical profession in relation to a high risk patient from 2003 until this year. Even if no ultrasound or MRI was done, you would think that at the very least a specific blood test to identify cancer would have been carried out on a routine basis. The lack of action and monitoring and lack of responsibility on their part continues. No-one has yet explained why they needed to recheck the ultrasound scan from last year.

#### **Section 6: Treatment/Care/Support**

21. [H] and I have been co-reliant upon one another for support.

**Section 7: Financial Assistance**

22. [H] and I have commented on this issue in our respective First Statements.

**Section 8: Other Issues**

23. There are no other issues.

**Anonymity, disclosure and redaction**

24. I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry. I do not wish to give oral evidence at the Inquiry.

**Statement of Truth**

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

Signed... [GRO-B] .....

Dated ... 11/09/2019 .....