Witness Name: GRO-B
Statement No: WITN1143001
Exhibits: WITN1143002
Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST 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 the GRO-B GRO-B

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are exhibited to this statement in the medical chronology.

Section 2. How Infected

3. I was tested at GRO-B before exploratory and a operation and I was told that I have Factor IX (FIX) clotting deficiency. I was therefore diagnosed with Haemophilia B also known as "Christmas Disease". There was and is no evidence of bleeding in my everyday life but it was considered I should have precautionary treatments for any future operations.

4. My medical records show that I received blood clotting agent FIX before and after a GRO-B at GRO-B I was also given more FIX in 1984 during a minor operation at my

local GRO-B Interestingly the only other minor operation since was in 2018 (for an in-grown toenail) for which I was prescribed Tranexamic acid, not FIX clotting factor.

5. I do not recall any information or advice being given to me at any time regarding the risks from exposure to infected blood products, neither do my parents and there is no discussion of this in any of my medical records.

6. I do not think there was a collective coherent view for many years as to what information to give me and whether this should be acted on in terms of treatment, especially because as the years went on I saw such a variety of clinicians. Sometimes the view seemed to be that I appeared well and there was no point in being treated; other clinicians took the view that I may as well be treated.

7. I recall a Haemophilia clinic at GRO-B in GRO-B in which it was explained that I might have been exposed to Hepatitis C (HCV) antibodies (no discussion of HIV) but I think it was downplayed and no information was given to me regarding how to manage the infection. Certainly no distinction at that time was made between exposure to HCV and the presence of chronic HCV infection, though in my medical notes, a letter from the clinic to my GRO-B dated GRO-B states "clearly he is at risk of developing chronic liver disease in the future". A copy of this letter is exhibited at **"WITN1143002"**. At the time I did not know that. It was not until GRO-B that the presence (and long-term risks) of HCV infection was fully confirmed to me. I recall feeling quite emotional on my return to university having had a further appointment at the Haemophilia clinic. I am educated, but a layman in medical matters. I was given no information about the risks of infecting other people, indeed the only information I had was from a book that my mother kindly bought me, "Living With Hepatitis C". I could not face reading the book, I just assumed the worst and always thought that I should be 100% careful in my dealings with other people.

Section 3. Other Infections

8. As far as other infections go, recent tests i.e. GRO-B show that I do not have HIV. I see from my medical notes that I declined to be informed (I do not recall declining to know - but that is what my notes say) of whether batches of clotting factor that I had been treated with were also infected with vCJD. Though the same medical notes it was confirmed that I was not treated with FIX infected with vCJD. Of course, like many others in this position, I have always had at the back of my mind that cocktail of possibilities of HIV, HCV and vCJD.

Section 4. Consent

9. In terms of consent, and the possibility of experimentation, that is hard to know. Prima facie evidence appears genuine enough that I had a 43% FIX count, at GRO-B assuming that test was correct and correctly interpreted, that does mean that I have the "Christmas Disease".

10. However, as previously stated, when I had a minor operation in GRO-B I was not given FIX (by chance I had an appointment with Gastroenterology just before the operation and the consultant simply prescribed Tranexamie, to be taken orally as required) and the fact is that I have never experienced any excessive bleeding from cuts and scrapes. In fact my wounds from the toe operation healed very quickly and nicely and I did not need to take a single painkiller. I required no Tranexamie acid either.

11. A letter from my Consultant Haematologist at GRO-B in early GRO-B describes my re-tested FIX levels as at "our normal lower limit" and "the question as to whether GRO-B does or does not have Christmas disease remains unresolved", I note an entry in GRO-B from GRO-B that a FIX test showed a score of only 10% (this led to a delay in a planned lung biopsy). Either my levels of FIX vary wildly from time to time or the tests in those earlier days were inaccurate. But the possibility remains that I was given clotting factor - infected clotting factor - when perhaps it wasn't required, twice at GRO-B and once at GRO-B

Section 5. Impact of the Infection

12. I'm one of the luckier ones in that my chronic HCV infection did not affect me directly in the physical sense, though I am aware that the scarring on my liver was a cause for concern and might, unchecked, have developed into a more serious condition. I believe that was a factor in selecting me for treatment with GRO-B or 8 weeks in GRO-B This left me feeling fatigued, constipated and sick with frequent headaches, to the point that my GP signed me off work towards the end of the course. The very large pills I had to take distressed me as unfortunately I have a phobia about swallowing pills, so each of these times was something of an ordeal. In fairness, I was offered support in this regard, but this would have delayed the start of what I felt was a unique window of opportunity offered to me.

13. Mentally, the impact of HCV was huge, sometimes in its own right and sometimes combined with the existing fears, insecurities and concerns common to us all. I avoided physical relationships for fear of infecting others. I did not want to be in a position of having to explain the risks to potential partners. I remain single, unmarried and without ever having had a family of my own. I adopted a fatalistic approach to life, barely concerning myself with work and career progression (despite my A-Levels, BA & MA) as frankly I wondered how long I would live, or at least maintain a reasonable level of good health. The situation was not helped by a merry-go-round of different clinicians, some more familiar with my case than others, some clearly reading my notes in front of me - the outcomes of appointments ranged from wait-and see as I'm apparently healthy to telling me I had an enlarged spleen and scarring on the liver.

14. I kept these concerns from my parents as I felt that during my childhood, they had already been through enough - to a young couple being told to take me home from GRO-B and treat me as a "normal" baby, when having a baby with GRO-B GRO-B must have seemed anything but normal to them. So my later determination to protect them from anxieties regarding HCV

meant the fear remained all mine, that once more, this time with me as an adult, they would have to watch me ill and in distress, or ultimately lose me. For years the prospect of their grief and loss was worse to me than anything I might have suffered.

Section 6. Treatment/care/support

15. It took until GRO-B for treatment to start the treatment as I was not happy with an incident about 8 years before when the lead nurse seemed more interested in giving me marketing and promotional material from the drugs company concerned than in making herself available for us to discuss when any treatment might start. After several phone calls not being returned, I lost confidence in what was already a stressful situation, the course offered to me would have been 6 months of self-injection with a likely 60% success rate but with possible side-effects. I didn't re-engage with the possibility of treatment for years after that.

Section 7. Financial Assistance

16. In GRO-B I received a one-off Stage 1 payment of £20,000 from the Skipton Fund.

17. Since GRO-B I have received regular Stage 1 payments of approximately £4,000 from Skipton (later EIBSS) and an annual Winter Fuel Payment of £519. Additionally, from April GRO-B an income-based top up from EIBSS of approximately £4,500.

18. I did apply for the Special Category Mechanism (SCM) payments in GRO-B and appealed when my application was not successful. In this instance I felt the case I was making was one I had to make largely in the dark. The Government seemed to be suggesting that I might have suffered from HCV infection but at the same time turned me down when I provided evidence of that suffering, despite my consultant agreeing that it was "certainly possible" and my GP writing a very supportive letter on my behalf when I appealed. I was robust enough to accept the 2 unsuccessful applications, but I do wonder what the effect on that process was on others.

19. In relation to SCM, I have always found the process of applying relatively straightforward and any queries to Skipton and then EIBSS have been answered promptly, courteously and thoroughly. I know not everyone feels this way, but I find them very supportive.

Anonymity, disclosure and redaction

20. I confirm that I do wish to apply for anonymity.

21. I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed..... GRO-B .....

Dated 12/03/19

Medical Summary

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

Virology Results

02.06.1994	Hepatitis C Antibody screening test Reactive	
02.06.1994	Hepatitis A IgG:	Not detected No evidence of past Hep A
02.06.1994	Hepatitis C IgG: Ortho EIA: Murex EIA: Final Result:	 Positive Positive Positive
15.08.1995	HCV Genotype: Type 3a	

Significant Entries/Absent Entries