Witness Name: GRO-B
Statement No: WITN4007001
Exhibits: 0
Dated: MARCH 2020

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 I was born on GRO-B and I live at GRO-B GRO-B

2. I was infected with the Hepatitis C Virus (HCV) from contaminated blood products.

3. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How infected

4. I have severe Haemophilia A. I was diagnosed with haemophilia at the age of two at the Lincoln County Hospital when I accidentally cut myself biting into a glass bottle. I am first generation British of Bangladeshi origin. I am the first known haemophiliac in the family. My parents spoke little English and had a limited understanding of the health implications for me.

5. I was treated at the Treliske Hospital in Truro, Cornwall under the care of Dr Helena Daly and Dr Kruger for the best part of my childhood. I was treated with Cryoprecipitate and a variety of Factor VIII (FVIII) products. My father had to drive me to and from the hospital for treatment. I was not allowed to have home treatment (administered by my father) until I was in my teens although Dr Daly fought for me to have it sooner.

6. No advice or warning about the risk of infection from treatment with blood products was given beforehand to my parents.

7. I cannot remember a specific conversation informing me that I had HCV. I do not think that my parents were aware of it for a long time. If they had been told, they wouldn't have understood the implications (and gravity) of me being infected with HCV. My parents respected and trusted the doctors. I was brought up being told that the 'doctors know best' and to be compliant in accepting treatment. Haemophilia, spontaneous bleeds and treatment were just accepted by me as being second nature to my childhood.

8. I transferred to the Southampton Haemophilia Centre at the University Hospital Southampton during my university years. I then transferred to St Thomas' Hospital in London. I am currently treated there by Dr Maden but I have had several consultants previously to include Dr Rangarajan and Dr GRO-D

9. I wasn't aware of having HCV until I transferred to St Thomas Hospital. I suffer with rheumatoid arthritis and require physiotherapy and so I was under the care of multiple teams. I believe that I was kept in the dark about having HCV until my mid twenties. The haemophilia outpatient appointments were brief bi-annual meetings. You had a quick check-up and then you were out of the door. You invariably saw a different doctor at each appointment but I started to pick up on the issue from the odd comment made.

10. At one appointment, Dr GRO-D spoke to me and told me that there was HCV treatment available for me. I wasn't provided with any information about HCV and/or how to manage the condition. I wasn't even provided with any written material on the subject. No-one told me about when I had been infected. The doctors at St Thomas' Hospital did not want to speculate but I think it was mentioned that I could have been infected with HCV from when I was around the age of 13. After being informed that there was HCV treatment available for me, I was referred to the Hepatology Department and Dr Wong.

11. I was training to be a broker in the City. Because of the perceived lifestyle of a broker, Dr Wong asked me if I was a heavy drinker. I was informed that the life expectancy of someone with liver cirrhosis through HCV and alcohol abuse is about 30 years. I wasn't given adequate information about HCV until I was referred to Dr Wong.

12. Because of my upbringing I have always steered clear of drugs, alcohol and a partying lifestyle. Nevertheless my liver levels were reported to be high and it made me think about my own mortality and the importance of pursuing a healthy lifestyle. I now worry and stress about my health and my parents also worry and are very protective of me.

Section 3. Other Infections

13. I was handed a letter more than a decade ago informing me that I may have been exposed to vCJD. The explanation was brief and the affects were diluted. The doctors didn't have much time to see me and couldn't give me much by way of further information.

Section 4. Consent

14. I was clearly tested for HCV without my knowledge and consent and without my parent's knowledge and consent. We did not know that I was infected with HCV for what was probably in excess of ten years from being infected. I had

countless hospital appointments and blood was taken from me on many occasions. I erroneously assumed it was for the sole purpose of monitoring and treating my haemophilia.

15. I also believe it likely that I was treated with a variety of FVIII products for research purposes. I was a young and vulnerable, previously untreated patient. English was not the first language of my parents and there was a lot of Asian condemnation. I was in and out of hospital with bumps and bruises and my parents were suspected of abuse. In essence, before my haemophilia diagnosis was made, my parents were in danger of having their children removed from their care and it was a very difficult time for them.

16. Because of their background and heritage, my parents would have bent over backwards out of reverence and respect for those in authority and particularly the doctors responsible for my care. My parents would have trusted the word of the doctors and if they had wanted to give me X, Y or Z, my father would have agreed and readily said yes to any form of treatment or testing that the doctors said was needed albeit it is unlikely he would really have understood what the advice was, given the language barrier. However I am sure that the information surrounding the purpose of the treatment and tests and the repercussions of the treatment would not have been shared with my parents.

Section 5. Impact of the Infection

17. I had a course of Interferon treatment for a significant period of time (6 or 12 months) when in my mid to late twenties. The treatment was extremely aggressive. I had to self-inject an epipen into my lower abdomen and now have a very dark scar under my stomach. The treatment put me in a similar condition to having flu. I was exhausted and could not concentrate. As stated, I was training as a broker in the City. As a broker, you have to be sharp in order to function at a high level and I ended up having to leave.

18. As stated, I was on treatment for a significant period of time and I was unable to work. I felt too ill. I did not claim benefits and was wholly reliant upon my

savings to get by. I was definitely adversely impacted financially. I then had to return to work before I was really up to it (albeit taking a less demanding role as a private banker).

19. After quite a long period of time and several tests, I was told that I was clear of HCV in 2012.

20. There is a huge amount of stigma associated with HIV/AIDS and HCV is synonymous to it in the eyes of the Asian community. It has been very stressful for my parents. Whilst they are proud that I am a hard working and relatively healthy son, they have struggled to understand and come to terms with the worry of it. It is not something we can share with others.

21. I am 37 years old and am single. My friends are in long term relationships and/or have families. I attribute my marital status to having been infected with HCV. Because of the stigma I find it difficult to confide in a potential partner and I have issues with intimacy. Whilst I have now cleared the virus, I was treated with what I thought was a clean product and it was anything but. I always try to see the good in others, especially professionals and I trusted my doctors.

Section 6. Treatment/care/support

22. Neither my parents nor I were offered any kind of counselling or psychological support.

23. I am particularly disappointed with the lack of support from the Haemophilia Society. As a member I would have expected more from a charity than a monthly newsletter.

Section 7. Financial Assistance

24. I received a payment of £20,000 from the Skipton Fund in or around 2002 but didn't fully understand what it was for at the time. My memory is that my father dealt with the paperwork but, given his difficulties with the English language, he did not fully understand what the payment was about either.

25. It has only very recently come to my attention that I might have been entitled to further payments/income and I am in the process of claiming the monies due from EIBSS. I am disappointed that this wasn't brought to my attention sooner. As stated, I have struggled financially and it would have taken so much pressure from me to have been in receipt of what I understand to be substantial monthly payments to include energy payments.

Anonymity

26. I would like to remain anonymous. I wish to provide oral evidence to the Inquiry on an anonymous basis.

Statement of Truth

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

GRO-B

Signed…………………………………………….

16th March 2020

Dated…………………………………………….