Witness Name: GRO-B
Statement No: WITN1294001
Exhibits: 0
Dated: May 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 wasinfected with the Hepatitis C Virus (HCV) through 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, diagnosed when I was a baby. My mother's uncle had haemophilia and, being aware of that, she had a feeling that she might be a carrier.

5. I was treated at the Birmingham Children's Hospital (BCH) under Dr Hill. I was treated with Cryoprecipitate initially before moving on to Factor VIII (FVIII) treatment. I had a lot of treatment and from the late 1980s I started to have FVIII treatment from home. I treated my self if I felt a bleed coming on in my joints before going onto to treat myself every other day profolactic in the morning.

6. My parents were never given any warning of risk of exposure to infection from FVIII concentrate before I was given it as a treatment.

7. My parents found out that I was infected with HCV in 1994. We were going away on a family holiday to France and my parents had asked for a letter about my haemophilia treatment to make it easier for us to get through customs. The letter came a few days before our holiday and it also stated on it that I had HCV.

8. I was just 12 years old at the time and my parents didn't tell me that I had been infected with HCV when they received that letter. I remember how they reacted. They were angry about something to do with the letter and I didn't know why they were angry. My parents were very protective of me and we all went on holiday (my parents, my older sister and me) whilst my parents kept the news of my HCV diagnosis hidden from us.

9. I learned that I had HCV in 1996 when I was 14 years old and about to start Interferon treatment. My mother explained to me then that there had been an issue with the FVIII concentrate I had been treated with previously.

10. Prior to my parents finding out that I had HCV, my mother recalls one of my haemophilia doctors commenting to her that my liver function was OK. She didn't understand or appreciate what that was about at the time and thought it a bit odd. My parents should have been informed as soon as the doctors were aware of the problem.

11. There was no advice given about managing the infection at all. My parents had to wait for two years before the go ahead was given for me to have HCV clearing treatment.

Section 3. Other Infections

12. Many years later I received a letter notifying me that I had been exposed to the risk of vCJD. I then saw something about it on the ITV news. The thought that I might be infected with vCJD in addition to HCV left me cold. I had no follow up contact from the Haemophilia Centre on the matter. I was actually informed by my dentist at a routine dental appointment that I didn't have vCJD as I hadn't been exposed to any of the batches known to be at risk. I thought it wholly inappropriate to be flippantly informed of such an important matter, in passing, by my dentist.

13. I was by then under the Haemophilia Centre at the Queen Elizabeth Hospital in Birmingham. When I next saw my Consultant there, Dr Wilde he was with a a trainee doctor or his Registrar. I asked Dr Wilde for a word with him in private and I then raised the issue about my dentist and her comments ahead of him giving me the information himself. GRO-D GRO-D GRO-D

Section 4. Consent

14. I was tested for HCV without the knowledge and consent of my parents. I believe there to be a strong possibility in all the circumstances that I was tested for HIV but I cannot say for sure.

15. I am uncertain as to whether I was tested or treated for research purposes.

Section 5. Impact of the Infection

16. On being told by my mother that I was infected with HCV, we had to attend at BCH every day for a week before being sent home with the Interferon treatment. I was accustomed to self-injecting FVIII concentrate into my arm but the Interferon treatment was a tough call. I had to self inject it into my leg every night for six months.

17. The effect of the treatment was to make me feel awful. I was very tired and lethargic. I missed a lot of school and it affected my school work and grades. I then thought that there was no point in bothering to even try at school. I was used to joint pain but I remember having a terrible and very different pain in my stomach from the region of my liver. I would be in agony but I had no idea then that it was anything to do with the HCV infection and/or treatment. No-one had told me what to expect. When I saw Dr Hill at BCH he would also check around the region of my liver and I would wonder why he was doing that.

18. Through me being absent so much from school at that time, my classmates became curious as to why. I was rarely there whilst having the clearing treatment. It really affected my friendships. One of my school teachers took it upon himself to tell everyone in the class about my haemophilia. To do so was against the express wishes and instructions of my parents. The news that I had haemophilia and had become ill spread to other pupils and their parents. People then associated haemophilia with HIV/AIDS and I was stigmatised. It became a very serious issue for me. I remember very clearly one of my friends telling me to "Go away. We don't want AIDS". That incident and the attitude of my other friends had a deep and profound effect upon me. It left me with hate in my heart that shouldn't be there. After I left school the same "friends" would invite me over but I never went. I never saw them again and didn't want to either. I am pretty much a loner by nature. My personal life and the potential for relationships have most certainly been affected.

19. The mental, emotional and psychological effects upon me of being infected with HCV have been huge. My mental health has been severely impacted and I am on the Fluoxetine anti-depressant drugs.

20. I had huge problems with alcohol and gambling which became a serious addiction. Whatever money I ever had, I gambled away. I am certain that a large proportion of my alcohol and gambling addiction is directly attributable to being infected with HCV at the age of 12.

Section 6. Treatment/care/support

21. The Interferon treatment did work for me. I know it didn't work for a lot of people but for some strange reason it worked for me.

22. I believe that counselling for me was suggested to my mother by one of the doctors. I was just 14 years old and I wouldn't have wanted it at that time. I have since learned a lot about past trauma and it's association with complex addictions.

Section 7. Financial Assistance

23. In or around 2004 I received the Skipton Fund ex gratia one off payment of £20,000. Some time later I heard that the cost of my prescriptions would also be met but that was it for a long time. I would have suffered severe financial hardship if it were not for being fortunate enough to live with my parents. More recently (from in or around 2016) I was notified that I was entitled to an annual sum of approximately £3,500. That annual sum has now been substantially increased.

24. I would struggle without the income (now provided through EIBSS) because I am unable to work and I have encountered issues in claiming PIP. What the

Government gave with one hand they took away with the other. As a specific example I failed my PIP assessment and had my car (which gave me freedom) taken from me. Apparently there was a vote in the House of Commons as to whether haemophiliacs affected by the blood scandal should be exempt from PIP assessment and just go straight onto it. The vote did not succeed and we have to continue to be assessed.

25. I later read on a site that the Government were reviewing the haemophiliac and PIP issue so I phoned a number to ask about this. I was told that it was a good job that I had phoned as my name was on the review list. Two days later I received a letter saying I could have PIP but not the full amount to enable me to have a mobility car. I found this odd as I heard previously heard of a haemophiliac who had PIP denied only to be told later that he could have the higher amount backdated to the date it was initially denied.

Anonymity

26. I am seeking anonymity.

Statement of Truth

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

Signed…… **GRO-B** ………………..

Dated …29.05.2020……………………