Witness Name: GRO-B
Statement No: WITN5230001
Exhibits: 0
Dated: December 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 1953 and I live at GRO-B.

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

3. This witness statement has been prepared without the benefit of access to my medical records. I **spoke to a member of the Haemophilia staff (Nurse Charlotte) at my annual routine telephone appointment on 7th October 2020 and was given some limited information but I was informed that a lot of my medical notes had been destroyed in the mid-1980s.**

Section 2. How infected

4. I have mild Haemophilia A, diagnosed at 18 years old.

5. I was treated at the Leeds Haemophilia Centre at the St James University Hospital, initially under the care of Dr Swinburne and then Dr McVerry.

6. I was treated with a number of Factor VIII (FVIII) products in the early 1980s as follows:-

16-7-1981 - - - - Batch Number - HL2784 - - X 2
17-7-1981 - - - - Batch number- HL2784- - X 2

10-5-1983 - - - - Batch Number- HLA3024 - - X 2
18-5-1983 - - - - Batch Number- HLB2954 - - X 2
06-8-1983 - - - - Batch Number- HLA3024 - - X 2

20-6-1984 - - - - -Batch Number - HLB3104 - - X 3

7. I do not know the exact date or batch number of treatment culpable for the HCV infection, but I was told that it may have been known to the haemophilia clinic from as far back as 10th January 1983. Apparently, there is a notation on my notes which says something about a 'weak positive' (although it is non-specific as to what it relates to). It seems that Dr McVerry did not make extensive notes and sometimes there are only one-word entries and a lot of them are illegible or very hard to read.

8. Sometime in 1999, I was informed by Dr McVerry at a routine haemophilia appointment that I was infected with HCV. There is an entry on my notes that blood samples were taken for testing (for HCV and other things) on 18th February 1999 with a positive HCV test result being noted on 8th April 1999.

9. At being told that I had HCV by Dr McVerry I asked him what would happen next and I was shocked at this response. He bluntly told me 'there's not a lot we can do' and seeing as I had 'obviously been living with it for such a long time', he didn't 'see it as a problem'. I asked him the worst-case scenario and he informed me that if it got really bad, I would need a liver transplant. At which my wife (with me at the appointment) burst into tears. Moreover, I asked Mr McVerry if there was any possibility that I could have passed the infection on to my wife. He replied..'yes'. We then asked if she could be tested, to which he replied.... 'I suppose so'. He was very abrupt and unfriendly.

10. Dr McVerry seemed very uncaring and very blunt. I then asked him if it was a blood disease or a liver disease to be informed that HCV was a liver disease. I told him in no uncertain terms that if that was the case, I wasn't happy to receive treatment from him and demanded to see a liver specialist.

11. No information was given to me as to risk of infection from blood products. I was not given adequate information to help me understand and manage the infection. I am disgusted about the way both myself and my wife were informed of the positive HCV result, without sympathy. The small amount of information we received from Dr McVerry was pitiful. Moreover, we only learnt that information because we asked questions.

Section 3. Other Infections

12. I received a letter dated 1st March 2005 from the Haemophilia Unit at St James Hospital regarding a possible infection of variant Creutzfeldt-Jakob Disease (vCJD) through blood products. I did not look for further information. I researched it and knew that they could not test for vCJD and I did not see the point of pursuing anything that would bring up bad memories for me.

Section 4. Consent

13. I have been treated and tested without my knowledge and consent and without being given adequate and full information. I believe I have been treated and tested for the purposes of research.

14. 1 was not informed that I had HCV until 1999. I believe that it was known by Dr McVerry that I was infected as far back as 10th January 1983. Since then treatments and tests have been undertaken by Dr McVerry knowing that I have HCV. It has been one large cover up. It has been one Monumental cover up by The Haemophilia Depts, The Department of Health and the Government.

Section 5. Impact of the Infection

15. My wife and I were stressed and worried beyond belief at the thought of how this infection might affect our lives. We were upset and felt that we had been let down by the treatment at St James Hospital. We couldn't sleep properly, and both suffered with anxiety. I suffered with severe mood swings and hardly left the house unless absolutely necessary. I was required to return on a regular basis for further blood tests to ensure that the HCV infection had not returned. This continued for a number of years causing added anxiety and stress. Although I was given the all clear in 2003. I have found that even to this day, I still feel the effects of this traumatic time. The fact is that going over all this info regarding my HCV infection has brought back memories of a period of time I thought I'd locked away. I've found it very stressful and depressing. Although I know I am very lucky to have survived it. I can't help thinking **"What If".**

16. It's caused me to reflect. Causing anxiety and sleepless nights. I can't help constantly thinking about all the other people who have been infected and also affected by this awful negligence.

17. I now realise that the anxiety had never really gone away. Even to this day I have a distrust of any injectable products. I still get anxious whenever Blood infections or anything to do with injections are mentioned. I refuse to take the Flu vaccine, although I am offered it. This is all down to my experience with my HCV infection. And now we are to be offered a vaccine against Covid 19. In all honesty I do not trust the vaccine. Nobody knows what effects or problems it hides.

18. My wife suffers from severe epilepsy. She is diagnosed as having Tonic-Clonic seizures which can be life threatening. Any stress to her can be a trigger for an episode. Looking back over that period of time in our lives, we have remembered that my wife had multiple seizures including one which resulted in her hospitalisation for 1st and 3rd degree burns to her legs and needed skin grafts. We now think that the extra stress due to my HCV diagnosis, resulted in these seizures.

19. My life in general was thrown into chaos. Everyone around me was worried and anxious: worried regarding whether I would be able to receive treatment for the infection; what would my future be if I didn't receive treatment and whether it would be successful. Was I going to die? Had I infected my wife? The list was endless. I had to wait months for an appointment to see a liver specialist and, when I finally started under that care, I had to have blood test after blood test to be told that I had very high virus levels in my body. I then had the anxiety of wondering if they could do anything for me. All these things impacted greatly on my life. I had to inform those nearest and dearest to me of my infection and what it could mean and I worried in case I inadvertently infected anyone else accidentally. It was a nightmare.

20. I became solitary, immersed in my own thoughts as to the situation. We stopped socialising with friends and the wider family. It was devastating. I was told that if

I received a treatment and it didn't work, there would be no chance of me having another treatment.

21. I spent hour after hour on the Internet, researching the Infection and how it was affecting others and how some treatments didn't work for some individuals. People were dying from this all over the world through no fault of their own. It was a terrible time for all concerned. I couldn't understand why I had not been informed sooner that I had been infected. My mind was in bits. I became a different person. I couldn't sleep through worrying all the time. My whole life changed for the worse.

22. The stigma associated with having the infection was immense. Besides myself and my wife, I only told my children and other close family members and asked them not to tell anyone else. I was worried people would think I was a drug user, Injecting drugs into myself. After all, that was thought at the time by the majority to be the reason people catch HCV, wasn't it? I told my family I wanted it kept private. I couldn't work during my resulting treatment as I was too ill and suffered financially. The effects on wife, family and close friends was enormous. Everyone was upset and worried as to my condition. They suffered severe emotional stress and has had a lasting effect on them all. I have grandchildren and family members who suffer with haemophilia. They all are very wary and suspicious of blood products they may receive. This is all because of the fact that I myself was infected.

Section 6. Treatment/care/support

23. After telling Dr McVerry that I didn't want to be treated at his clinic, I was put under the care of Consultant of Hepatology, Dr C E Millson, and his Research Fellow Dr P Southern whom I saw several times between 8th October 1999 (the date of my first appointment) and 2003. I was treated with Interferon injections and Ribavirin tablets between November 2001 and June 2002.

24. I had to self-administer the treatment at home which I found very difficult to do. I have a huge dislike of needles and have to look away when they are being injected into me. I had to try to overcome this fear. Gradually as I got further into the treatment cycle, I experienced very bad/severe side effects from the medication, to the extent that the treatment had to be stopped early.

25. I lost lots of weight. I suffered with severe fatigue, tiredness and nausea and a lack of appetite to the point that I thought I was dying. Some days, I couldn't even take a few steps around the house. The effects on me and my family were devastating.

26. Although the treatment proved successful and I am now free from HCV, I have a lasting distrust of treatment for my Haemophilia. I no longer attend the Haemophilia Clinic. Instead, I maintain contact with them through annual telephone consultations. I need major dental work, but in order to have the work done I am required to attend the Leeds Dental Hospital under the supervision of the Haemophilia Department. Therefore, I have not had the work done. This is purely down to the mistrust of the treatment I received in relation to infected me with HCV.

27. I have never been offered counselling or psychological support with regard to me being infected with HCV. I was never aware there was any available.

Section 7. Financial Assistance

28. I was never made aware there was any financial assistance available from any Trusts or Funds. The first knowledge I had was when I read an email from my solicitors attaching the 'Request for evidence under Rule 9 of the Inquiry Rules 2006'

Anonymity, disclosure and redaction

29. I am seeking anonymity and understand this Statement will be published for the purposes of the Infected Blood Inquiry.

Statement of Truth

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

Signe GRO-B

Dated......22-1-2021