Witness Name: GRO-B
Statement No: WITN1487001
Exhibits: 0
Dated: 24 January 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. I was born on GRO-B and live at GRO-B with my husband. I am retired.

2. This statement has been prepared without the benefit of access to my medical records. I requested my medical records from the West Suffolk Hospital and Addenbrookes Hospital Cambridge. They have both been very unhelpful with their responses. For example, I have been referred to various different departments or have received no response at all.

3. I have been infected with Hepatitis C as a result of receiving contaminated blood products.

Section 2. How Infected

4. I suffer from Haemophilia Type B classed as severe. I was diagnosed at an early age and this would have been at Addenbrookes Hospital. I was treated with Cryoprecipitate early on, and then Factor VIII. I received Factor VIII as and when needed. The treatments were administered at hospital. When I needed an operation I travelled to West Suffolk Hospital. I was admitted for dental work in the 1970's and the removal of my gallbladder much later.

5. I don't remember the names of the medical professionals who treated me over the years. I was registered at a GP in GRO-B which is a small town 20 minutes away from where I live. I transferred to a GP closer to me more recently. I do not know over what period I was given contaminated blood products or which contaminated product gave me Hepatitis C.

6. I found out I was infected with Hepatitis C in the mid 1990's at Addenbrookes Hospital when I was undergoing blood tests as I was feeing unwell and looked very jaundiced, and was suffering from tiredness. They took an ultra-sound of my liver and found shaded marks which the doctors told me were Hepatitis C. There was no information given to me at the time or for a long time after. They did not warn me of any dangers of Hepatitis C, how to manage it or tell me how I managed to contract the disease. I believe this information should have been available and given as soon as the infection was diagnosed. The doctors also did not give me any information at the time of the risks of others being infected as a result of my infection.

7. At a later date a GRO-B gave me some information on the risks associated with Hepatitis C. On a later visit to Addenbrookes, GRO-B GRO-B gave me information on the transmission of Hepatitis C, however still no information was given to me about how I was infected.

Section 3. Other Infections

8. I received a letter about the possible risk of vCJD but ignored it as by this point I really didn't want to know if I had it or not.

Section 4. Consent

9. I was aware I was having tests, however I believe they were all diagnostic and not for research purposes. If they were for research I did not consent. I recollect they started making a fuss over my blood samples after I was diagnosed with Hepatitis C making sure the blood was labelled with a red sticker with '*Bio Hazard*' written on it.

Section 5. Impact of the Infection

10. The mental and physical effects of being infected with Hepatitis C were severe. It was very upsetting; the doctors just didn't talk to me or explain anything, their conduct was very poor and cold. I feel it has led me to problems with my mental health such as depression. I was ill for a long time. I suffer from Chronic Obstructive Pulmonary Disease (COPD) which flared up, in addition I was very fatigued and jaundiced and I had to have my gallbladder out. When I went to the doctor to talk about how ill I was, she turned around and said "*I can't help you as I don't understand you.*" Comments like this from a medical professional have a distressing effect. I suffered guilt as a result of the infection I thought it was not fair on the family, and this guilt was compounded with the potential risk the whole family could be infected. I didn't want to leave the house. At the same time my application for a Disabled blue badge was rejected it felt like it was all piling up and no one cared. This disease had a serious knock on effect for my husband and close family, and put them at risk too.

11. The news of the infection was earth shattering; there were two sides, the clinical and the psychological. The psychological aspect was the worst and so

was the feeling of not knowing what to do, or who I could turn to. I was informed about my infection in an insensitive, cold and clinical way. This was totally unacceptable. The doctors did not provide any information at the time about the risks posed to others being infected as a result of my infection.

12. I was originally offered Interferon treatment for my Hepatitis C; however, I declined the treatment due to reports from GRO-B who had tried it and experienced extreme side effects such as depression, suicidal thoughts, fever and headaches. I have recently finished a 12 week course of Harvoni, taking 2 pills a day for 12 weeks. In February of last year, I was given the all clear. This does not mean that my trauma is over because I was informed that there is a chance of recurrence and the physical and psychological effects of the disease are still prevalent. During treatment I experienced nausea and headaches.

13. I experienced obstacles in obtaining appropriate treatment. The Haemophilia clinic was based in the sexual health clinic at Addenbrookes Hospital. I was surrounded by school girls, drug addicts and people with exotic piercings. This made me feel uncomfortable and out of place. There were always long delays at the Clinic. There should have been a separate area for waiting or a private room to wait in. I have also experienced in obtaining dental treatment due to my infected status, as my dental work has to be carried out in a hospital as the local dentists wont touch me due to my Haemophilia and Hepatitis status.

14. My entire family GRO-B as have been affected and I had no one to turn to as a result. I have GRO-B who are Haemophiliacs and they also contracted Hepatitis C. I was always cautious about touching people for fear of passing it on. I would have preferred to have stayed at home away from people in the early days. I wanted to isolate myself. This did not have a positive effect on any aspect of life whether; private, family or social. The fact I was made to walk around the hospital with 'Bio Hazard' labels stuck on the bottles of blood I was carrying made me very conscious of everyone's perception which made me feel isolated.

15. I wasn't aware I was infected at school so it had no effect on my education. I worked full time, however, I started to have to take time off and this definitely affected my work. I wasn't eligible for paid time off so had to take unpaid absence which affected me finically. My employer was not accommodating, however when I came back to work they put me on reduced hours. Towards the end of my career they gave me job where I could sit down most of the time which helped my condition.

16. My husband had to take time off work to support me. The feeling of not being able to help made him angry, frustrated and extremely upset. This was exacerbated by the various inquiries which uncovered nothing and achieved nothing. This had a knock on effect on all our relatives, as although I share the infection with some of my relatives it is a hard topic for us to talk about.

Section 6. Treatment/Care/Support

17. As set out above, we have faced difficulties and long delays in obtaining treatment for the Hepatitis C.

18. I have not received or been made aware of any counselling or psychological support available to me. I believe that it should have been offered by the NHS. GRO-B provided some assistance at a later date, as she made herself open to talk to me about my infection.

Section 7. Financial Assistance

19. I have received a £20,000 stage 1 payment from the Skipton Trust. I found out that financial support was available through my family, many of whom are Haemophiliacs. No one at the hospital mentioned informed me that support was available either to me or my husband. We have applied for grants in the past; however, the applications were declined due to my husband working. These grants were for decorations and repairs, nothing extravagant.

20. The process of applying for such grants was on a means tested system with financial preconditions imposed. I believe this to be very wrong considering that our conditions were caused by the contaminated blood products. It should have been compensation rather than ex gratia payments. It made me feel like I had to beg cap in hand for the payments and I am not that type of person. When people are feeling depressed, and are in difficult place it should be easier to obtain assistance. I had a doctor's note to obtain the stage 1 payment however the application forms posed the wrong questions. They asked why you couldn't raise the capital yourself and you were always made to feel that you would not receive anything.

21. My GRO-B had to go to court to save his blue badge. I was awarded a blue badge myself however it was taken away due to new disability guidelines. This has put me off applying for assistance in the future. Overall I feel the various trusts and funds have complex application processes which are not well designed. The trusts have a distinct lack of transparency which results in you feeling beaten before you even start.

Section 8. Other Issues

22. I would use the phrase "*lack of transparency*" again. I cannot understand why you carry on using infected blood when you knew it was infected? The money from the Skipton Fund felt like it was just hush money. The difference in the amount awarded in Scotland and Ireland compared to the payments we receive is upsetting and unjustified. Haemophilia is something you have to live with, Hepatitis C was a condition we had to go through, why did I get it? Because the blood product I was given was contaminated. I have so many questions I want answered; why are there so little records of my treatment? Why did hospitals break their guidelines and destroy documentation? I want answers but most of all I just want someone to say sorry and for someone to explain how it happened.

Anonymity, disclosure and redaction

23. I would like to be anonymous and I would like not to give evidence.

Statement of Truth

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

Signed GRO-B

Dated 24/11/19