Witness Name: GRO-B
Statement No. WITN2831001
Dated:16th April 2019

# INFECTED BLOOD INQUIRY

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## FIRST WRITTEN STATEMENT OF GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 18th March 2019. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, GRO-B will say as follows:-

## 1. Introduction

1. My name is GRO-B my date of birth is GRO-B and my address is known to the Inquiry.
2. I am GRO-B and presently live alone.

## 2. How Infected

1. I am a severe haemophiliac and suffer with Haemophilia Type A.
2. The blood product I received is Factor VIII.

3. I have mostly attended at the GRO-B GRO-B GRO-B for any treatment in relation to my haemophilia. My treating Consultant was GRO-B I also remember being treated by GRO-B who was one of the nursing sisters at the GRO-B Apart from a period of about two years in about GRO-B when I was in my GRO-B I moved to GRO-B to work and attended at the GRO-B for treatment for my haemophilia until I returned to GRO-B

4. I believe I was given infected blood products from GRO-B up until the mid GRO-B

5. I am unsure as to what information (if any) was provided to my parents at the time. I was about GRO-B years old at the relevant time and had no knowledge or information of hepatitis C. I did not really get involved in talking to the doctors about my treatment as my parents took care of that.

6. I was infected with hepatitis B and C as a result of being given infected blood through the administration of Factor VIII products.

7. My parents and I found out that I had been infected with hepatitis C when GRO-B asked to see us at the haemophilia clinic at GRO-B I believe GRO-B knew that I had become infected a long time before we were told. Unfortunately I cannot check with my parents as they are both now deceased. The reason I believe this, is that as soon as we were told of my infection, I received extensive treatment with Interferon very quickly.

8. It was not until I was offered the Interferon treatment that the realisation hit me as to how serious my illness was. In GRO-B I underwent a year of Interferon and Ribavarin treatment. I had injections at the hospital until I learned how to self administer. I then injected myself in my stomach or at the top of my legs once a day. Sometimes whilst

injecting the needles would break. This happened a couple of times and I know it also happened to others. When this happened, you would just have to pull the needle out by hand. It would drag the skin away from your body when you pulled which was extremely painful. My infection cleared in the mid GRO-B I believe I still experience after effects of the Interferon as I suffer with migraines and believe these to be a side effect as I did not suffer with these before the treatment.

9. I do believe that information should have been provided to me earlier as this affected my life when forming close and intimate relationships. I had no information to give the other person. I could not answer their questions because I did not have the answers. I felt I was "kept in the dark".

10. When I was prescribed the Interferon, it was by GRO-B at the GRO-B He was brilliant and provided me with plenty of adequate information. Before that, in previous years, the hospital staff were very guarded, not much information was given out.

11 GRO-B advised me that there was a "slight risk" in relation to my partner becoming infected but that the risk was "almost next to nothing" and explained that my partner could be tested if she wanted to. She decided to be tested and fortunately the test was fine so I put this worry to the back of my mind.

12. My partner and I married in GRO-B after a GRO-B year relationship. Unfortunately we divorced after GRO-B years. My wife had GRO-B young children of which I am not the father,and I believe my infection put a strain on our marriage. My wife was frightened of me passing on the infection to her and to her children. It caused a huge rift between us. I then found out that my wife was having an affair. I believe we were pushed apart by the worry of it all. During my divorce, my wife tried to claim half of the first award I had received from the Skipton Fund but fortunately this was not allowed.

## 3. Other Infections

1. In GRO-B I became infected with hepatitis B, which fortunately cleared. At the end of GRO-B or the beginning of GRO-B I received a letter stating that I had been exposed to blood from an infected donor. The infection was vCJD, also known as "mad cow disease". I was really concerned at receiving this letter, so I attended at the GRO-B and saw GRO-B He confirmed that I had definitely been exposed to some of the infected blood but they would not know what the effects of this would be until I reached my 70's. He explained that I could suffer with dementia as a result of receiving this infected blood. I worry about my memory loss even now. If I cannot remember something I wonder whether it is the onset of dementia. It causes me anxiety and concern.

2. I believe I also became infected with HIV as well as hepatitis C. However the doctors told me that I managed to fight this infection off. They advised me that I have GRO-B immune system. Apparently there are only GRO-B people in the GRO-B who have this type of GRO-B immune system and this assisted me in fighting off the infection.

## 4. Consent

1. I believe that I have been tested without my knowledge and consent and without being given adequate information over the years, as it took so long for the information to be revealed. Each time I went for blood tests, they would take at least 8 vials of blood from me and I was never told why or given an explanation as to why they needed to take so many. Even to this day, I still ask what they are testing my blood for and still ask to be retested as I am worried the infection may come back. I had a friend who this happened to and it has made me anxious that there is a possibility the infection may return.

## 5. **Impact**

1. The mental impact my illness has had on my life is huge. I do not socialise any more. I have experienced quite a few knock backs in relationships, because I feel that I need to tell the person in the early part of the relationship, but when I tell them about my infection of hepatitis C they just do not want to know me anymore. They are frightened that they will become infected too. Even if I explain that I am no longer infected it does not seem to make a difference. They are too scared. I no longer try to form close relationships it is just not worth the heartbreak.

2. The social stigma is still very much prevalent in my local community. Even family members did not want to know us after my diagnosis. It caused a rift in my family. To this day, I still do not speak to aunties and cousins that distanced themselves as a result of my diagnosis. I believe it may be because of the stigma associated with hepatitis C i.e. drugs etc.

3. Further medical complications are an impaired liver. I undergo liver scans every couple of years. I have been told that my liver is a "bit fatty" but have been told not to panic as it is just tissue from the damage caused by the hepatitis C. My liver is now functioning normally. I also suffer extreme tiredness. It is not unusual for me to sleep from early afternoon until about 7.00 a.m. the next morning a couple of times per week. Since the Interferon treatment I have suffered with migraines at least 2-3 times per week and believe these are related to the Interferon treatment.

4. I have also been exposed to vCJD infection as a result of infected blood and experience extreme joint pain in my ankles and knees and have arthritis in my fingers and thumb.

5. I have not experienced any problem in accessing treatment. Interferon was offered to me as a "test" drug. I was asked did I want to try it and believe I was one of the GRO-B to try it out at the GRO-B

6. I am not aware of any other treatments which ought to have been (but were not) made available to me.

7. As a result of my infection of hepatitis C and the liver damage it caused, it has limited my access to treatments for my arthritis. In relation to dental treatment, I used to have to go to the GRO-B for dental treatments but now there is no problem in attending any dentist in my locality.

8. I feel the stigma of my infection did impact on me and my family. I remember a family in my locality of GRO-B who had two sons of around 7 and 8 years old who became infected with hepatitis C. They were treated like lepers by their neighbours. The neighbours made their lives hell. I did not want that to happen to us and believe my infection was kept quiet because of the fear of something like this happening.

9. In the last years of my school life when I was about GRO-B I was home schooled. Although I do not feel it held my back academically, I still missed out on the interaction with the other students. It also limited the social aspect of growing up as the only friends I had were the ones who lived by my home.

10. I believe I lost quite a few job opportunities as a result of my illness. I would explain at job interviews about my haemophilia. I would let them know that my haemophilia was under control with regular medication and this did not seem to be a problem, but as soon as I told them about my infection of hepatitis C, they did not want to know me. I felt as if I had a "black mark" over me.

11. I have been unemployed since GRO-B I was advised by one of the doctors that because of the extensive joint pain, that I should not work as the pressure and excessive strain was too much on my ankle and knee joints. The doctor told me that I could be in a wheelchair by the time I reached 25. Fortunately this had not happened yet.

12. There has been obvious hardship as a result of not being able to work, however I had an award from the Skipton Fund in late GRO-B in the sum of £20,000 which helped.

13. As I do not socialise any more I now tend to take up interests which I can either do alone or only involve a limited number of people. I am a member of the GRO-B and can GRO-B However I find that because of the extreme tiredness I now suffer with, I can only GRO-B GRO-B at a time. I would not have the energy to fly to a destination and then fly back. I need the co-pilot to pilot the return flight.

## 6. Treatment/Care/Support

1. I have recently been offered counselling through my social worker at the GRO-B because I am suffering with depression and my mental health is not good. I have decided to attend and I am waiting for an appointment.

## 7. Financial Assistance

1. I found out about financial assistance through the GRO-B I was then contacted by letter from the Skipton Fund (now the GRO-B GRO-B and invited to apply for an award, which I did. I received a Stage 1 payment in late 1990 of £20,000.

2. More recently, whilst completing a PIP application with the help of my social worker from GRO-B she suggested that I apply for a further Stage 2 award in light of my liver damage and my mental state. I did

this and qualified to have an "add on" from Skipton GRO-B of £18,500 per year. This "add on" will begin on the 20th April 2019.

3. I did not experience any difficulty in applying for the Stage 1 and 2 awards.

4. In relation the amount of financial assistance available, I believe that people are not receiving the payments they deserve and are not being compensated properly for their shortened lives due to no fault of their own.

## 8. Other issues

1. I consider myself very lucky that I cleared my infection of hepatitis C. There are others that I knew who were not so lucky and unfortunately died through no fault of their own.

**Statement of Truth**

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

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

Dated... 16 . 4 . 2019 ........