

Witness Name: GRO-B

Statement No.: WITN0177001

Dated: 18<sup>th</sup> January 2019

## INFECTED BLOOD INQUIRY

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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 16 November 2018.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name, date of birth and address are known to the Inquiry. I am a 53-year-old woman still suffering the after effects of having been infected with Hepatitis C for most of my life. I intend to speak about my own experiences of having been infected with Hepatitis C and how it has impacted most of my life.
  
2. I should have had a healthier life, even with the disabilities I have but, as a result of being infected with Hepatitis C, it has completely changed my life. The last 9 or 10 years, and even before this, have been extremely difficult due to feeling ill most of the time and not knowing why.

## **Section 2. How Infected**

3. I was infected with Hepatitis C by having two blood transfusions at Kidderminster General Hospital, Worcestershire on 10 October 1980 after a road traffic accident where I suffered severe head injuries. I was 15 years old. Prior to receiving the transfusions, no advice was given to my parents or myself about the risk of infection from blood transfusions.
4. It was only in 2016 when I started to lose my hair (it was breaking off and falling out) that my GP started to investigate. My GP took blood tests that showed elevated liver levels, though she wasn't concerned initially as she thought it might correct itself as she thought perhaps I just had a virus. I believe it was about two months or more before she had me tested for Hepatitis C.
5. My GP diagnosed me with Hepatitis C, having not previously known I had received blood transfusions. No information was offered on how to manage or understand my infection, apart from to avoid sharing personal items. I was given only some information about the risk of passing the infection to others, which seemed to focus on sexual contact and using personal items. When I eventually saw the liver nurse, she explained the infection to me. No advice was given on diet or nutrition in order to help manage the symptoms, which I find shocking. I was only told to eat healthy.
6. I felt I should have had blood tests for this many years ago and that I should have been informed by my GP or through the hospital that I was at risk for infection because of my blood transfusions. I was never informed about these risks. I was totally unaware of the risks and never saw anything in the media, on TV or about the Penrose Inquiry at that time.

7. After having my first positive blood test result, I got re-tested to make sure it was not a false positive. I was very anxious and I was left all alone without any understanding of this infection or what it might mean for me whilst I waited for the results for about two weeks. I was worried about being infected with Hepatitis C, but I was also worried about the possibility of having HIV too.
8. The GP I usually see was very sympathetic but my registered GP was not at all sympathetic about how I felt and even had the receptionist call me about the tests rather than telling me himself! I was horrified at this! I really felt ashamed by it all, even though it was not my fault that I had been infected. I didn't want anyone else to know! I felt my condition should have been treated more confidentially and not shared with the receptionists at the surgery.

### **Section 3. Other Infections**

9. I am still worried that I may have been exposed to other infections, such as vCJD, apart from the Hepatitis C I was infected with through the blood transfusions. I am concerned that there may be something that has not been found yet that could surface in years to come and that I am unaware of. I am also very concerned about the likelihood of damage to my other organs or brain from the virus.

### **Section 4. Consent**

10. I believe and feel that I have been treated without my knowledge or consent. Although my parents would have given their consent for the blood transfusion at the time, they were not informed of any risks of infection. My treatment may or may not have been for the purpose of research, I do not know for sure.

### **Section 5. Impact**

11. My symptoms started around 2009, though some were present even earlier. My weight increased considerably and I could not lose weight no matter what I did and this was unusual for me. I also experienced itching all over my body for a few years. I had severe stomach pain and inflammation, reflux and digestive upsets, trouble swallowing and being unable to eat because it made me feel so ill. I had bloating for many years. I had gallstones. I had dry lips, too. I had more joint pain when my virus was active, including knee pain in both knees and hip pain and inflammation, which has never healed properly. I felt this was caused by the Hepatitis C infection. I had more pain and inflammation than I should have experienced.
12. I had noticeable changes in memory, which, although already bad, I felt like I had Dementia. I would ask a question and then after a few minutes ask the same question, sometimes two or three times as if the answer just hadn't sunk in at all. I would forget to eat unless I am reminded in some way. I would forget where I was sometimes and what I was doing. My memory got much worse in 2016/2017. I did not discuss this with my GP at the time because my GP never has enough time to go over all my issues, but I was very worried it might have been the start of Dementia. I found out later, after I was diagnosed, that this was called "Brain Fog" and that the Hepatitis C caused this.
13. I experienced elevated stress and anxiety, including mood swings. I also had higher blood pressure that started around the same time as my other Hepatitis C associated symptoms. I experienced fatigue and weakness

and feeling very unwell throughout my whole body. I had fatigue when I woke up and was fatigued during the day. The daily fatigue was so bad that I could not do much at all in the way of activities and so this had more of an effect on my overall health and fitness. It was so bad that I had no life in me to do anything. The fatigue got much worse in the last couple of years and I would drop off all the time, even when I was eating dinner!

14. I was always feeling very ill and this lasted for years. I had good days, but I was ill more often than I was well. I had lots of undiagnosed problems over the years and my GP never had the time to talk or to deal with all my symptoms. I just felt burdened by having so much to deal with all at once and never really getting things properly diagnosed when I did see the doctor and most of the time I just feel like giving up!
15. I developed Bruxism in approximately 2015 or 2016. I was diagnosed with Raynaud's Syndrome in 2017, though symptoms had started late in 2016. I know that the inflammation caused by Hepatitis C can cause Raynaud's Syndrome. Since the symptoms started, my feet are icy cold, numb and white most of the time. Some symptoms persist even now, including extreme sensitivity to cold temperatures and I always feel very cold. This has actually increased over the last two years, despite treatment for the Hepatitis C.
16. I still have digestive problems and pain in my right side even now. I continue to have nerve problems, which I believe are a result of the Hepatitis C. I have paraesthesia in my head, arms, hands, legs and feet. The paraesthesia in my head only started in 2015 I believe and has been less since the Hepatitis C medication, though it has not completely gone. I have more pain and inflammation in my back along with numbness and paraesthesia symptoms that have got worse over the years I was ill with all of this. My back pain was getting worse prior to treatment and was very bad in early 2017 and has left me with more paraesthesia as a result.

17. I still experience many of the physical symptoms described. I still experience fatigue and I am sometimes unable to do normal activities. My memory is still worse than it was before, although the brain fog lifted with treatment for the Hepatitis C. I still feel the Hepatitis C impairs my memory. I have also lost a lot of weight and I am still losing weight without dieting which is a worry.
18. I am still very emotional about the whole experience and get very upset about having been so ill for so long and struggling with so many health issues. I still get depressed and upset and it effects me every day. I do not like seeing the doctor, but it has been necessary so often over the years. I was never diagnosed with depression, though my GP did, I believe, offer a mental health nurse appointment even before I was diagnosed with Hepatitis C because of the stress of being so ill. It felt like I was going to have a bit of a breakdown. However, with all the other things to discuss with my GP we never had time to talk about everything and I did not want to have the stigma of another label attached to me. I still have episodes of feeling low and anxious and it has been very up and down over the years. I am still worried about what else might go wrong and the potential of long-term damage to my liver and other organs as a result of having undiagnosed Hepatitis C for 37 years!
19. The infection has had a huge impact on my life and has shocked me so much. I have felt suicidal at times and only because of the infection. I also got very nervous and jumpy all the time, I was constantly on edge as if something was always about to frighten me. I was confused a lot of the time and had to work very hard just to remember even the slightest thing. Before my infection, I was always very calm.

20. From my own research, I am aware of the studies that show I am at greater risk of developing heart disease and diabetes after having Hepatitis C for a long time. I am also aware that Hepatitis C puts pressure on all the other organs. I am aware that it causes an increased risk of high blood pressure and have experienced this myself as I do have hypertension. I am aware that Hepatitis C causes stress and anxiety due to the virus crossing the blood brain barrier. I wrote a report for my GP and the liver consultant about Hepatitis C and its effects so that they could learn more about it and pass on that knowledge and hopefully help others.
21. Being infected with Hepatitis C has had a huge impact on my private and social life. My friends knew I was ill but I could not tell most of them what was wrong. When I told close friends, some reacted badly and did not want to see me after finding out. One of my closest friends reacted this way and would not see me until I was cured and this left me so upset and in tears. I was worried that if people found out I was contagious that they would not want to know me anymore.
22. Because there is so much stigma still associated with Hepatitis C, I felt and still feel unable to tell anyone. Most of my friends and relations do not know about my diagnosis because I do not know how they will react. I really need to talk to someone about it all but I cannot confide in anyone.
23. In the immediate time after my diagnosis, I was so worried about the risk to anyone who visited me that I got obsessed with bleaching everything daily. I was also worried and upset that I could have infected others in the past.
24. If I had been fit for work then the Hepatitis C would certainly have prevented me from working once it took a hold of me. Financially, I have been impacted by needing more money for heating and spent the winters

almost freezing because I could not afford to put the heat on anymore. I also had to pay out of my own money to see a private liver consultant after being diagnosed with Hepatitis C because the wait with the NHS would have been too long. The wait was causing me too much stress as I needed answers urgently and my GP didn't have a clue. I feel I should have had the opportunity to discuss things with someone sooner and that if I had done at the time of the tests and diagnosis then I would have felt reassured and suffered less from stress.

25. The impact for my family and friends has been great for those aware of my infection. They have worried greatly about the fact I was infected because of the transfusions I had.

#### **Section 6. Treatment/Care/Support**

26. My treatment started 15 March 2017. My medication was Solvadi (400mg once per day in the morning) and Ribavirin (200/400mg twice per day). The symptoms I experienced on this medication included dizziness/vertigo, feeling very tired, poor coordination, bad headaches on a daily basis and just feeling weird overall. I had a fast pulse and it felt like my heart was racing and I had higher than normal blood pressure. I experienced insomnia, which was very bad. I felt strange in the morning after the Solvadi pills.
27. After the Ribavirin pills, I would get hot flushes that started after the nightly pill around 8pm every night and I had never had hot flushes until this time. I also experienced a lot of ear pain and strange feelings in the ears after taking the nightly Ribavirin pills. I felt very short of breath and had chest tightness and my lungs felt very bad. I had a very bad cough and would feel very breathless on slopes or stairs. I felt like I was drugged. I felt wiped out and my fatigue was worse. I would get skin rashes like psoriasis. My leg and arm muscles were much worse and I had weird sensations and twitching that I had never experienced before. These



sensations contributed to my lack of sleep, as well as the insomnia. I found it very hard to concentrate on things and my vision was affected, too. I felt paranoid and angry. I was very depressed and very wired up and just mentally not myself. My hair and skin was very dry and itchy. I also experienced nausea and central nervous system issues.

28. After stopping the medication in June this year, I continued to experience the hot flushes at night, almost as if my body has got used to that. The depression and moodiness took some time but did lessen a few days after stopping the medications. The rage and paranoia stopped as soon as I stopped the medication. The cough and breathlessness continued for a while until July this year I was no longer woken up by the coughing. However, I still have a rash on my face and scalp and still have nerve issues. This is not as bad as when I was on the medication, but is much worse than before I had the medication. I had vertigo again earlier this year (2018) and that lasted for 7 months and left me unable to do much as it was so severe. I am unsure if the vertigo was an after-effect of the medications. I also discovered I have some hearing loss, which may be a result of the medications, but I am still seeing an audiologist about this and waiting for the full report.
29. I did face obstacles in obtaining treatment for my Hepatitis C. I had to wait from October until April to get the new Solvadi and wait for the board (I don't know exactly who they were) to decide if I was getting it or not. The wait was frustrating and made me more anxious. I had to visit the hospital to get more medication after my supply ran out and I felt this was an inconvenience and that I should have been given enough at the start! Also, I had a long NHS wait to see a liver consultant so I paid to see a private one as the wait was causing too much stress. I did not have support when I was diagnosed and I felt I would have benefited from support at that time as I definitely feel I needed more support initially, as well as during and after treatment. I was too anxious to understand

everything that was said to me and I was unsure if I would die quickly from it at that time. Psychological support was not offered to me. The only support I got was from the Hepatitis C helpline where I could chat on the phone, which I found myself. I feel I needed more care as I had to rely on others to do most things for me.

- 30. I am unsure if other treatments were available to me, but I was never presented with other new treatments.
- 31. I was worried about telling my dentist about being infected, as I did not want anyone to know.

#### **Section 7. Financial Assistance**

- 32. My liver nurse told me about the Skipton Fund and that I should apply. I received £20,000 from the fund on 20 June 2016 and receive monthly discretionary payments of £252.50.
- 33. I later applied for the higher rate Special Category Mechanism (SCM) payments and had to complete another application form and have my GP fill it in too. This was for the additional complications of my Hepatitis C infection. When the system changed, I received the same amount of £252.50 per month from EIBSS instead and then I applied for the financial top up payments in August 2018 and now receive £1,862 per month from EIBSS.
- 34. Before I could receive payments there were preconditions I had to meet. I had to find proof of having the transfusions, which was not easy to locate. My GP's records did not show the transfusions so I had to have medical records search for them. Finding the records also had a bad impact on me because it was upsetting reading about the road traffic accident when I was 15 and reading things I never saw when it occurred.

35. I do not feel that the small amount of financial support received is in anyway close to acceptable, considering the fact that I have been infected with Hepatitis C most of my life and due to no fault of my own. In no way does this amount of discretionary payment pay for the damage caused to my health, previously or in the future.
36. I am concerned about the NHS involvement with the financial payments because of cutbacks. I wonder how long these payments last and nobody has been able to answer me yet.

### **Section 8. Other Issues**

37. Even now, I feel neglected. I am supposed to have yearly liver scans to check for the damage caused by the Hepatitis C but my last appointment has been cancelled and delayed now by three months. I waste time chasing them and still don't know anymore and I feel that is unacceptable.
38. I am concerned about on-going care from a liver specialist. Since I paid to privately see a liver doctor, I have never seen another doctor. I do see a liver nurse and she is very good. At first I thought she was a doctor, but she is not. I think that on-going care ought to include seeing a doctor and I really feel I should have seen one on the NHS.
39. I also think that there should be more awareness that not only the liver is affected. The second payments made for financial support are only made for cancer of the liver, but there are other cancers and dire effects on other organs that are not considered and for which there is no help. I think it is important that people are aware of this.
40. I need guarantees that I will be looked after and given the support I need, financially or with related health issues as a consequence of being infected. I also feel that those who have been infected with infected blood

products should be given free prescriptions because of the other health problems caused by infection. We should get more support in general.

**Statement of Truth**

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

Signed

GRO-B

Dated 18<sup>th</sup> January 2019