Witness Name: GRO-B Statement No: WITN3166001 Dated: 7<sup>th</sup> June 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 17<sup>th</sup> April 2019. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, GRO-B , will say as follows:-

#### 1. Introduction

- My name is Mrs GRO-B
   My date of birth is the GRO-B
   and my address is known to the Inquiry. I am a GRO-B
   GRO-B
   I'm married with two children. My son is 12 years old and has severe special needs and my daughter is 10.
- 2. My statement will be related to my Mum, **GRO-B: M**, who was infected with hepatitis C via a blood transfusion in the 1980s after receiving contaminated blood products.

### 2. How affected

- 1. My Mum, M , was infected with hepatitis C. My Mum received two blood transfusions one in 1986 and one in 1988 so it's possible that she could have been infected twice. She was treated in GRO-B in GRO-B No advice was given about the risks of infection prior to the transfusions. My Mum was told that she had hepatitis C thirteen years later. The Consultant that informed her of the infection in her blood totally played it down and she was not made aware of just how serious and dangerous this "infection" was. Maybe the doctors didn't have the information at the time, but then again, no further details were provided to my Mum after they knew more.
- 2. In 1986 my Mum had been feeling unwell and she was told by her GP that she had a kidney infection. As she was so unwell, my family knew that something wasn't right with her so took her to A&E at GRO-B. While she was in A&E her ovary burst. She had an undetected ectopic pregnancy and was rushed to theatre where she was given her first blood transfusion. Doctors didn't think that she was going to make it but thankfully she did. They said that she was lucky to have been in the hospital as she would have died if it had happened at home.
- 3. In 1987, Mum was told that as her ovary had burst, she couldn't have any more pregnancies; however, she did get pregnant within the following year. Unfortunately, after the birth she haemorrhaged and became really ill and received eight pints of blood during another blood transfusion. The doctors again warned my Mum not to have more kids and so my Dad ended up getting sterilised.
- 4. After the second transfusion she was often unwell and was going to the doctors a lot. By this time my parents were raising my nephew as carers as he had been diagnosed with special needs at six months old. He was a very unsettled baby, and my parents were given the responsibility of caring for him at 39/40 years old. My Mum would get tired a lot, but she just thought that it was the

stress of my nephew and being grandparents. My Dad was working all the time while my Mum looked after my nephew. She didn't sleep and was constantly tired and unwell.

- 5. Mum continued to go to the doctors, and they would often ask her how much alcohol she was consuming as her liver levels were high. My Mum had never had alcohol in her life. As she had to keep going back to the hospital, she became even more lethargic and depressed. I was 15 at the time, so there was a lot of responsibility on me as my older siblings had left home. I had to look after the baby as my Mum was that unwell that she just physically couldn't.
- 6. In around 2002, she visited the doctors again and they asked again how much alcohol she was consuming. At this point my Mum became angry because she had already told them that she didn't drink and eventually the doctor sent her to the hospital for tests. The doctor at the GP surgery told my Mum that the test results were showing that there was something wrong with her and that she . She was transferred to the GRO-B couldn't go back to **GRO-B** in GRO-B for further tests and a liver biopsy. A few weeks later GRO-B they sent for my Mum again to have a second biopsy of her liver as they said they didn't get enough the first time. As they wanted to keep her in overnight I had to stay off school and go with her so that my Dad could stay at home with my nephew. **GRO-B** is 80 miles from where we live so the commute was hard, and with my Mum being extremely nervous and unwell, it wasn't a choice to send her alone.
- 7. Not long after the tests in **GRO-B** I remember my Dad phoning me and saying that there was something wrong with Mum and that the doctors had told her that she had some kind of infection. I remember my father coming home from work saying that she had an infection called hepatitis C. My Mum didn't know anything more than that, and the doctors at the hospital even asked her if my Dad had been sleeping around. The next thing I recall happening after that is my Mum going into the hospital for treatment and her being extremely sick for what seemed like a long time. I had assumed that it was something that could

be cleared up with antibiotics but given just how long and sick my Mum was, I knew that it was more than just a minor infection.

#### 3. Other infections

1. My Mum's health has seriously deteriorated as a result of her hepatitis C infection, and she has suffered side effects because of it. She had to have a stimulator put in her brain ten years ago. She has had it changed once and will have to have it changed again at some point. The discs in her back are falling apart, she has osteoporosis, and her muscles are wearing away; she lives in her bed in constant pain. My Mum suffers from chronic migraines and insomnia which is either from the hepatitis C, or the treatment, or both. It's a vicious circle. She has diabetes and has had so many operations all due to ill health. I believe that the headaches are from the interferon treatment, as well as the stress from her muscles and joint pain, which aren't helped by her anxiety.

#### 4. Consent

1. My Mum's doctor at her GP surgery began investigating because she was visiting him a lot with her being so young and constantly sick. Thankfully, he sent her for further tests as he knew something wasn't right, which meant that the hepatitis C was detected.

#### 5. Impact

I have 4 other siblings. Our lives have been completely torn apart; two of my siblings have nothing to do with the family. There has been a lot of resentment and tension from my siblings towards my Mum as she has always been sick. My Mum's mental health has been seriously affected as a result of the hepatitis

 the trauma of it all – including the period before her diagnosis, being diagnosed, and receiving the treatment of interferon. It's like she's been served a life sentence; my Mum doesn't have a life, she just exists. It has meant a lot of arguments in my family that have never been resolved. Everything went

back to Mum being sick. Things just festered, and it got to the point that things were said that couldn't be unsaid. Bridges were burnt. I'd say we have a very messed up family, although I understand that every family has its problems.

- 2. With the huge split in our family, it has put a lot of responsibility on me, from back when I was just turning a teenager and my mother being diagnosed right up to now as my parents are dependent on my husband and me. I look at the hand they have been dealt in life and it honestly makes me so sad. My mother was robbed of her life, my father of his wife, and us of our mother. Their grandkids have never known my mother not to be sick or my father not to be a caregiver. I want to fight their corner which is why I have attended the Inquiry hearings and the local meetings. My Dad has had to give up work and they don't own their own house. There's nothing left over so they don't have holidays or any luxuries. They are both in their 60's and the youngest child living with them is twelve. Life revolves around my Mum and her being sick, and the problems it has caused.
- 3. Growing up money was really tight. I got a Saturday job when I was thirteen. I would get £12 for a day's work, and I would give my parents £10 and keep £2 for myself. At sixteen I got my National Insurance number and got my first real job. I'd go to school and then to work straight after school. I tried to help my parents as much as I could. I think that it's good because these experiences have made me hard-working. My husband has said that I would work a minute's silence, but I feel that I don't have a choice.
- 4. After my Mum's diagnosis, the doctors were very worried about my brother as she had the first transfusion before he was born. Thankfully he wasn't infected. My Dad was also tested as they initially thought that the infection had come from him. Our family were told not to tell anyone that my Mum had hepatitis C. As a result of the infection my Mum stopped going out, she was depressed, and became obsessed with cleaning which I believe is attributed to OCD. She lived on her nerves at that time and became dependent on anti-depressants. She depends on Valium as she shakes so badly.

- 5. I remember being in the chemist and the staff used to argue about who would serve my Mum. As an adult I would never let that happen but at the time, as a teenager, I used to be embarrassed for her. My Mum is so quiet so she wouldn't stand up for herself even though she was treated like a leper. Those serving my Mum in shops wouldn't hand her the change and would instead put it on the counter.
- 6. There was a lot of resentment at home as Mum was so down. I'm sure she was angry. My Dad is a man's man, so he didn't talk much about his feelings. My younger brother was only 11 years old, so it was an extremely tough time. The infection caused problems between my parents before the hepatitis C was diagnosed. As she was sick with different illnesses and visiting the doctors a lot, my Dad used to call my Mum a hypochondriac. This led to a lot of issues, and my Mum used to think that she was going crazy as no one would listen to her before she was diagnosed.
- 7. Growing up as children we didn't have much of a social life. My Mum didn't have one at all, as she was married very young and started a family. My parents were still young, and their lives were only beginning. They had so many plans. They thought that by having children young they would be able to enjoy their lives and have careers whilst we would be of school age. At thirty-four Mum's health was deteriorating badly and she had no life. Her eventual diagnosis with hepatitis C and the treatment eventually killed a part of her. She has never gotten over that.
- 8. I feel sorry for my daughter as she's very close to my Mum but all she knows is her grandma being sick. I look at her and I see myself in that she worries so much about my Mum. She won't go out to play and she just wants to be with my Mum. My daughter will go down to help Mum if she's unwell. I feel that my children have been robbed of a grandma and, although she's not deceased, she has no quality of life at all.
- 9. I'm a real worrier and I think far too much. I think it comes from the responsibilities I had when I was younger and because I didn't have my Mum

to look after me as a teenager. My life has been and still is a constant worry. My Mum had a mental breakdown and was put into a mental institution when my nephew was about six. Everything just became far too much. My Mum was so unwell and my Dad was trying to take care of her. They just couldn't do it anymore, so my nephew had to go into care. My parents never got over that. As my nephew grew older he became violent, giving my Mum black eyes, and he had to be fostered by a couple. The couple also couldn't cope with him, and he was thirteen when my parents got the phone call that he had been sectioned. He was eventually sent away to an institution in England which has had a devastating effect on our family. We believe it was all because of the hepatitis C and the after-effects of the treatment in that my Mum couldn't look after him.

- 10.1 still look after my Mum but I don't resent this as she's my Mum. I now have to look after my Dad too which I've never had to do until recently, as he is now getting old.
- 11.1 suffer from depression and anxiety myself. I never got to be a teenager and, just like my Mum, I don't drink. I didn't get to be free and do what I wanted, I had responsibilities at home to help my parents. We all got a sentence, but my Mum got a life sentence. My life revolved around my nephew and having to raise him before and after my Mum was diagnosed. I had to grow up fast. My school life was heavily affected, and I didn't get the chance to go to university. I would be in school dreading what I was going home to.

#### 6. Treatment/ Care Support

 I'm not sure of the timeframe in which my Mum received treatment. She was diagnosed around 2002 or 2003, so it was around that time. I was still a teenager and all we knew when she started the treatment was that it was a serious virus in her blood, and we were very worried. We couldn't kiss her, use the same toothbrushes, or touch her cutlery. If we fell and were bleeding, we couldn't let Mum touch us and we couldn't touch her if she was bleeding. I believe that when they gave her the treatment, they killed a part of my mother. I

used to keep diaries, and looking back on them I'm shocked at what I wrote in them at such a young age. I used to write that I missed my Mum as she wasn't the same. I was essentially grieving for a woman who was still alive. My diary revolved around her being sick. I remember having to bring needles from the fridge to inject my Mum. She was hardly ever awake, maybe for just an hour here or there. I remember also bringing her a basin for her to be sick in or having to take her to the toilet. It was like this for months. She was there in a vegetative state. Her hepatitis C diagnosis also caused new conditions.

- 2. As my Mum was in the hospital my Dad had to take care of the household. Dad can't cook or clean and was used to coming home from work and having his dinner on the table. Dad and I also had a young disabled child to look after with no money coming in. I was only 16 and couldn't cook or run a household and I remember learning how the washing machine worked. I had to look after a screaming child and take the bus 80 miles away to GRO-B to visit my Mum. I remember looking at her and thinking that she was going to die; I didn't recognise her. This was the first time I knew that her infection was serious. She would be sweating and hallucinating. I remember her telling me that the nurses were trying to kill her while she was rolling around in bed. I had never seen her in that state before. I was told by the nurses that this was just the side effects of the medication. I don't know how long she was on the medication for.
- 3. I don't believe Mum had difficulties in getting treatment. At the time it was a new treatment, and she was one of the first to get it, so she was lucky. She understood that some people weren't so lucky. There were no treatments that ought to have been available to her that I am aware of. I think at the time, when TV and news wasn't at our fingertips like it is now, there was less information available; however, I do feel that the medical professionals failed my Mum. It makes me angry. Anything that my Mum has problems with I Google straight away. My parents are very easy-going and trusting people. If you tell my Dad a white wall is green, he would believe it. They were just happy that she was alive and took everything they were told as gospel.

4. I think that the way my Mum was told that she had hepatitis C was inhumane. As a mother myself I would do anything to protect my children and I can't imagine how my Mum felt finding out. The manner in which she was told was wrong. Obviously, they needed to tell us what was happening, but there's ways and means. She was literally made to feel disgusting and dirty.

#### 7. Financial Assistance

 My Mum received £20,000 in the early 2000's from the Skipton Fund and in the last two years she's been receiving £4,500 a year. Her doctor put her forward for financial assistance, telling her to send her part of the application away and he would send his. I don't think it was a problem as she applied for it and got it.

#### 8. Other issues

1. I think that those infected deserve justice and that people need to be held accountable. I believe that this wasn't just an accident. Considering the places where the blood was from, I think there were bound to be problems. The least that those responsible can do now is hold their hands up and accept responsibility. Not only for infecting people, but for how it has been handled and how they were treated. These people were served a life sentence and us, as the affected, lost part of those people and our lives have also been affected. For it to take this long to be at this stage is disgusting. People still have to fight to be heard. They are considered worthless and like they don't matter.

### **Statement of Truth**

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

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Signed		L .	 	

Dated.Oct 26, 2022