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Witness Name: GRO-B

Statement No.: WITN0341001

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 December 2018.

I, GRO-B will say as follows: -

Introduction

1. My name is GRO-B I was born on GRO-B 1973. My address is known to the Inquiry. I am the daughter of GRO-B:M who died of liver failure on GRO-B 2018. I intend to speak about Mum and her experience of Hepatitis C, (HCV). In particular, the nature of her illness, how the illness affected her, the treatment she received and the impact it had on her and her life and on me and other members of my family.
2. Before she became ill, Mum worked full time. She was employed by both the Railways and GRO-B She was a keen cyclist and rode for a club. Mum and dad had three children: GRO-B and myself.

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How Affected

3. Mum developed bowel cancer in her twenties and was treated for this at Crewe Memorial Hospital. She was under the care of Mr Hassel. However, Mum was not actually told that she had cancer until the 1980s.
4. In the summer of 1965, she underwent major surgery to remove half her bowel. During the operation, Mum lost a quantity of blood and was given a blood transfusion to replace this loss. I cannot remember how long she was in hospital nor how much blood she lost as she never talked about the transfusion.
5. Following this operation Mum went to a local convalescent home for approximately three months, in order to recover. Upon leaving the convalescent home she went to stay with her mum. My sister GRO-B was born in 1966, one year after the operation.
6. In the late 1980s, Mum found out that she had previously had cancer. Following a visit to her GP she was referred to a consultant due to reoccurring blood in her stools. The consultant at that time told her that this was unconnected with her previous cancer. That was the first time she had been made aware of the cancer. I think the consultant probably thought Mum also knew about the cancer.
7. It was not until March 1999 that Mum found out that she had HCV. I am able to confirm this as I have seen a letter from her GP informing her that her blood test had shown the HCV virus. I am unable to say why she went to her GP for a blood test. I presume she went as she was concerned about her tiredness or as result of the pains she was experiencing in her side at that time.

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8. Following this, Mum was sent to Leighton Hospital and was treated by Dr London. She first saw him in February 2000. Dr London was a gastroenterologist at Leighton Hospital. They did not have a dedicated liver consultant here. I do not know how long Mum saw Dr London before being treated by the liver specialists at Birmingham University Hospital as well, which is a much bigger hospital. By this time, Crewe Memorial Hospital had closed.

9. It was in October 1999 that Mum was told that she had been infected with HCV from the blood transfusion she had been given in 1965. I do not know how this was discovered. I presume the doctors went through a process of elimination; my Dad was Mum's only partner, Mum had never been abroad and was not a drug user.

10. I am not sure what advice Mum received about HCV or how to manage it. Equally, I am unsure whether the information she was given was adequate or should have been provided to her earlier. I believe Mum probably did receive some advice as she was very conscious of the risk of contaminating others. Mum's worst fear was that she might have contaminated her children and her grandchildren, particularly GRO-B and myself who were born after she had received the infected blood. I understand that there is a higher chance of blood-to-blood transmission during childbirth. I remember how much Mum cried after the diagnosis, her family were everything to her and she did everything for us. Mum must have also been worried about contaminating my Dad. However, that is not something I would know as they were very private people and didn't discuss such matters. I believe Mum must have been given information about what to do, but I am not sure. Mum was certainly well read and would have researched it in any event. Dad still to this day will not discuss such things with us so we still don't know.

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Consent

11. It is my belief that Mum may have been tested for HCV without her knowledge. It would appear she had a test for HCV out of the blue in 1999. The doctors may have known about the HCV in the 1980s, as mentioned above, when they first informed her she had previously had bowel cancer. I would like to know if the test for HCV in 1999 was done as standard or whether the doctors were investigating something more specific as they already knew about it. It upsets me that Mum may have benefitted from earlier treatment had she been told about the HCV, rather than it lying undetected for such a long time.

12. Mum would have consented to the HCV treatment as she would have done anything to be clear of it.

Impact

13. My recollection was that Mum was always so tired and would constantly be asleep. She would come home from work and sleep throughout the evening. She used to sleep a lot at weekends waking up late. This was particularly difficult for Mum as she had a full-time job, three children and a house to run. The tiredness was always there. She had little energy to do anything. It is hard to say whether the tiredness got worse following the treatment for HCV as she had other treatments before she was diagnosed with HCV in 1999. This included having her gall bladder removed and being sterilised.

14. In March 2000, Mum had a liver biopsy and they discovered that she had an enlarged liver. I know this as her GP, Dr GRO-B wrote to her on 11th March 2000 to inform her that she was going to have a liver biopsy. I have seen the request for the liver biopsy in the handwritten

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contemporaneous notes Mum kept. She tended to write everything down as her memory was shocking.

15. The various treatments Mum was given for the HCV made her quite ill. She was told about the risk of feeling poorly due to the side effects, but experiencing it was a completely different matter altogether. The first treatment was in August or September 2000. I recall it was just before I married in 2001 and this course of treatment lasted for nine months, it should have been 12 months but it made her so ill she had to finish it early. I think it ended in May or June 2001. I believe the treatment she received was Ribavirin and Interferon. She may have also been given Pegatron. I have some memory of her injecting herself in the stomach during this course of treatment. I vaguely remember that Dad had to do it on occasions because she did not like injecting herself. Mum's condition deteriorated after this treatment.
16. The effects of the treatment was that it made her terribly ill. When she was on the medication, she had difficulty in getting off the sofa at home. She was so sick and tired all the time, Mum had little energy to do anything. She vomited a lot and turned a dreadful colour; I remember her eyes turned yellow and can recall thinking how unusual this was. The treatment severely drained her and was completely debilitating. She was so ill that I thought she was going to die.
17. My hope was that this treatment would to work and be the only treatment Mum would need, but unfortunately later tests showed that it had failed. This was in light of Mum having taken the whole course of treatment despite how unwell it had made her.
18. Following this, things went quiet for a number of years until around 2014 or 2015, when Mum was offered a new HCV treatment. No other treatment was offered in the intervening period. She may have been offered Ribavirin and Interferon but she couldn't tolerate them so would not take them again. Mum requested a new treatment she had read

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about following information sent to her by her nephew in the USA. I believe she wouldn't have been offered this, it was only because she asked for it they agreed for her to have it. However, four days into the new treatment, she collapsed at home as one of the varices in her throat burst. She was taken to Leighton Hospital and was admitted for a period of two weeks. She was bleeding internally and coughing blood. This nearly killed her. Mum was therefore unable to complete the treatment and was left with the HCV.

19. Mum restarted the treatment the following year. As she was in her late 70s and in view of the side effects she had previously experienced, we wanted her to decline the treatment. However, she was desperate to be rid of the HCV and travelled to Birmingham on the train for fortnightly treatment. The treatment was Harvoni in tablet form. The treatment lasted three or six months and finished in August 2016. Mum was then told the HCV was in remission. The side effects were not as bad as the treatment she had in 2000/2001. It was exhausting, particularly because she had to have lots of tests and travel to the hospital to collect the medication. In September 2016, she was told that she continued to be in remission. She then had to have a check-up every six months. As Mum became more ill, I asked the doctors to do more for her at the hospitals in Crewe rather than making her travel to Birmingham University Hospital, which was hard for her. As a result, they decided to scan her liver once a year rather than every six months.

20. Two weeks after the third course of HCV treatment, Mum was told that she had Parkinson's disease, developing the symptoms one year later. The medication given to her for Parkinson's disease caused her to have dreadful hallucinations. I believe the HCV contributed to her developing Parkinson's disease and ultimately the connected dementia. The damage to Mum's liver caused by the HCV restricted the doctors' options of how to treat her and it meant she had to have the more aggressive medication for Parkinson's disease. In October 2016 mum fell over and broke both of her wrists and banged her head this required

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stitches and she spent time in a rehabilitation home. She also fell again in October 2017 breaking her ribs. After a long stay in hospital, she eventually had to go into a private nursing home in February 2018 following this fall.

21. Mum had to deal with the fact that she only had half her bowel due to the original surgery. The HCV and the constant tiredness made dealing with this harder. This meant that she had no real quality of life.
22. Mum could not take certain medication because of the effect it would have on her liver. If the pain or her bowel was playing up, the doctors had to be careful as to what medication they prescribed for her. The liver damage caused by her being infected with HCV therefore complicated her treatment.
23. Mum's memory was not great and as result she wrote everything down to assist her. I have twenty of her diaries from the last twenty years. Her poor memory meant that she was so fearful that she would forget, she would write things like 'collect the grandchildren and feed them' and she would note all of her medications. Mum's memory deteriorated when she developed Parkinson's disease.
24. Following the fall, it was only a matter of months before Mum's health deteriorated further, leading to chronic cirrhosis of the liver (B1/T1). She was told that this was due to the damage caused by having HCV, but at that stage she did not have liver failure. Mum had numerous scans of her liver at the hospital.
25. Mum would regularly have to be given iron transfusions for iron deficiency as iron tablets constipated her. This in turn affected her bowel and she had to have blood tests to check her iron levels and blood pressure.

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26. In recent years, I had noticed Mum's jaundice. I could see that her liver was not working because of her increased memory loss and her skin was yellow with the toxins.
27. Mum was admitted to hospital in 8th June 2018 she was unconscious and unresponsive, she was given laxatives to try and clear her of toxins. We were told that this would keep happening because of her liver condition. She was re-admitted on 30th June 2018, the doctors told us that she had just two weeks to live. She died of liver failure ten days later on 12 July 2018. Mum had Hepatic Encephalitis caused by the toxins from her liver. This was just before she died. Liver failure was recorded on her death certificate.
28. Due to the complications and liver damage, Mum was only able to have limited painkillers at the end of her life. Further to this, she broke her leg and needed an operation on her hip. However, it was decided that she was too unwell to have the surgery.
29. I remember Mum was cold most of the time; her hands and feet were always freezing. Her hands were white and this was particularly worse during winter. She did not like being in the sun and would get prickly heat. Whilst this hadn't been a problem in her youth when out cycling, it was now something she additionally had to contend with. I understand now that these may be HCV symptoms.
30. Due to her conditions and symptoms, including the tiredness, Mum could not exercise and had a constant battle with putting on weight. However, she later lost four stone whilst in hospital.
31. When Mum was first diagnosed with HCV she was very worried that she may have contaminated her children and grandchildren. She would have wanted to have been told that she had HCV earlier as she was so frightened that she was not going to see her children grow up, which she desperately wanted to do. Mum cried and cried. She begged my

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sister GRO-B and me to get tested for HCV. GRO-B and Mum was upset about that too. Our family was Mum's whole life. It is very likely that she did not display outwardly everything that she was feeling in order to protect us.

32. Mum felt so ashamed that she had HCV; she felt like a leper. We were all told not to discuss it outside of the house as she did not want others to know. She never brought it up in conversation. She did not want others to think about how she contracted HCV; she was ashamed of what such speculation might imply about what her or my Dad could have done to get it. She was born in 1939 and was from a simple, hardworking family. She was very straight-laced and prudish. She was very much 'Miss Prim' and did not want to be thought of as 'one of those girls' or a 'good time girl'. Mum did not want to be judged. She was very private and did not want people to know her business. The stigma Mum felt is clear as she had lots of leaflets about Parkinson's disease, but had no leaflets or other literature or paraphernalia about HCV. Her private nature meant that I often did not know what was going on in her head. Even her cousins at her funeral did not know that she had HCV. Mum would have either refused to be part of this Public Inquiry or would have applied for anonymity at best.
33. The tiredness Mum experienced due to the HCV would have had a profound mental impact. She was always too tired to have a social life, hobbies or do anything else outside of work. She spent her time working full-time or being at home as she prioritised her family life. This would have been hard for her because she used to cycle a lot. She would cycle everywhere in her younger days and was a member of the GRO-B cycling club. Mum was very fit in her youth and used to cycle up mountains in North Wales. Her family were all sporty. However, she could do very little after she was infected with Hepatitis C. After that, doing anything physical was a really big effort.

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34. Mum had to miss a few hours of my wedding as she was so ill due to the side effects of the first course of treatment for HCV. She was not really well enough to be there. She was upset because she was too exhausted to help with the wedding planning as she had wanted to. I tried to drag her around to wedding planning appointments, but she was too tired. She managed to attend the major things, including my wedding dress fittings but could not help with the little details as she would tire her out for days afterwards. She missed out on most of the things a mother would have done which really upset her.
35. Mum at times missed out on helping with my young children as it was too hard for her. My son [GRO-C] when he was young and was [GRO-C] [GRO-C]. She helped with him, but it again tired her out. This was especially difficult for Mum because she had missed out on helping with my older sisters' children, having worked full-time when they were young.
36. Whilst a gregarious person, she did not suffer from anxiety when young. Although she was introverted and not very self-confident to a point, the shame of being diagnosed with HCV made this worse and held her back. The illness and tiredness combined with having to constantly think about it meant that she stopped moving forward with the things she wanted to do. Her energy and motivation were gone. She used to travel a lot on her own. However, she could not travel far because she could not get over the jet lag and it would take a long time for her to recover. She did not travel as much as she would have liked, which meant that she was too unwell to visit her sister who lived in America.
37. Shortly after my wedding, my maternal grandmother had a stroke. She was in her eighties. This would have been a particularly stressful time for my Mum. Mum's symptoms got worse and she was devastated that the treatment did not work, but she had other things to deal with. She wanted Nan to live with us, but she was unable to and died in 2005. Mum was absorbed with caring for Nan. She felt the responsibility fell

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to her as her siblings had moved away. She put her life on hold and just got on with it. However, it must have been hard for her to go from 2000 to 2015 knowing that she had HCV and not having any treatment for it.

38. Mum retired aged fifty-eight in 2002. This was around the same time as her first treatment for HCV and my wedding. The negative experience and side effects of the treatment clearly influenced her decision to retire.
39. Mum was miserable as she was so tired all of the time. She would fall asleep in the middle of the afternoon when she was supposed to be looking after her grandchildren. The tiredness made her grumpy and irritable. She was a strong character and sometimes she pushed herself too much.
40. Once Mum was diagnosed with HCV, she never had an alcoholic drink again. Whilst she didn't drink heavily before the diagnosis as it would give her bad hangovers and have an adverse effect, she would have a whiskey on a Wednesday night at the bingo and one at Christmas.
41. Mum would only eat plain food, what we would describe as beige coloured food. This would typically include meat and vegetables.
42. In October 2017, following her fall, Mum was unable to go home and was moved between the hospital and the nursing home. She also lost her independence and gave up driving in the last few years of her life. She used to say that she couldn't do anything to help me out and that she felt there was a role reversal for the children. She was determined to get better and always fought the HCV, but that also made her feel sad and depressed.
43. Mum was dealt a horrible hand. Living with her bowel condition meant that sometimes she needed to go to the toilet immediately. The

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combination of Mum's bowel condition and HCV made her life very difficult.

44. By the time she had the fall, Mum would say that she was 'bloody fed up'. She was quite a character and extremely funny at times. Her catchphrase was 'I never asked for any of this, and I don't want it'. It was all too much for her and she cried all the time in hospital towards the end of her life.
45. Mum did not really blame anyone for giving her HCV, but she was saddened by what had happened to her, especially as she had done nothing wrong; she had led a blameless life and never did anything immoral or illegal.
46. The stigma of having HCV was such that even if there had been a support group, I do not think that Mum would have attended. We tried to take her to a support group for Parkinson's disease, but she was in denial and would not engage. She would not have wanted to have been seen at an HCV support group.
47. The last two years have been awful. I have spent a lot of time going to the hospital with Mum on a weekly basis. We are all emotionally drained following the loss of the person we had. It feels that our loss is premature because her parents lived until they were aged ninety and eighty-eight respectively.
48. I am aware of the stigma of HCV. I recall the vicar at Mum's funeral say that she was the first person with HCV with whom he had dealt.
49. It was distressing to see Mum so ill with the side effects of the HCV treatments. In the final six weeks of her life, there was a noticeable change in Mum. It was distressing to watch her in constant pain, albeit she had a high pain threshold. This was harder as she got older

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because she ached all over and had swollen legs. My family and I were very nervous and worried about Mum when she went for the third course of treatment. We were concerned that she would have similar side effects to the previous two treatments.

50. As a child, it was hard to compare my childhood to my friends' because they were able to go out and do stuff with their families. I could not go out with Mum because she just wanted to stay in and watch the television. When we watched television together, she could not stay awake through a programme and so we would have to tape everything for her to catch up later. When we did have plans to go out, Mum would say 'leave me here, go off and do the things that you want'. She was too tired to join in and could only do so much. If we were to go shopping as mothers and daughters often do, we could only go for a certain amount of time because she would quickly become exhausted. Now that I have had my own children, I look back and realise that we did not do things together whilst I was a teenager. I did not know any different at the time, but I now realise that I missed out. I look back and realise that this was not right.
51. I remember Mum was unable to fully participate on Christmas Day each year as she was so exhausted after lunch she could not play party games with us.
52. Mum's illness made us independent. She would say that it was important that we knew how to look after ourselves from a young age because she did not know how long she was going to be around for. She used to say 'you have to be able to do it yourself' and 'if I'm not here, you can't expect someone to look after three children'.
53. As a child, the onus to look after me fell to my older sisters. This was at a time when fathers were not 'hands on'. Therefore, my older sisters ran the household. GRO-B picked me up from school. Mum could not pick me up or volunteer with any of the school activities. My sisters would

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cook dinner, GRO-B would cook full roast dinners from the age of eleven. My Nan lived close to us and used to help us when I was young. We would often go to her house for dinner after school.

54. When GRO-B and GRO-B left home, I had to become more self-sufficient. My Mum did not want to put people out so I had to be independent. I remember noticing at my friends' houses how all of their ironing was done and put away and that dinner would be made, whereas this wasn't the same in our house due to Mum's tiredness. Mum occasionally cooked stews and casseroles that did not involve much effort.
55. Mum's symptoms and illnesses made it very difficult. It probably caused disputes, but it is hard to know if that was the norm. Mum was depressed and negative. She was loving, generous and would do anything for you, however her outlook was negative. Mum was anxious about everything and she always had to be prepared for everything. At the time, I put the arguments this caused between us down to me being a teenager and Mum being menopausal. However, I now look back on this time differently.
56. I did not feel that I could burden Mum with any of my emotional problems. She did not have time for that. Prior to me divorcing my ex-husband, I told my Mum that it was going to happen but I did not talk it through with her. Mum was able to offer some support, but the emotional support was not there. Such problems were something else for her to worry about beyond her health. Mum was a worrier, but her health problems put my emotional problems into perspective. She certainly did not have time to entertain smaller, minor problems, such as problems with friends at school. Her stock phrase was 'tell me, I'll forget', which meant that you could tell her all about it but, because her memory was so poor that she would forget it.
57. Mum's memory loss was frustrating at times. Sometimes I would have to ask her three times to do something. If we made plans to meet, I

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would have to just hope that she would be in the right place at the right time.

58. Watching Mum deteriorate from the bright young person she was to the shell of a person she became at the end of her life was hard on my Dad. He found it too distressing to visit it her at the end. He has never recovered from it and feels guilty. He is frail, eighty and ill himself. For many years he acted as her carer and this has taken everything out of my Dad emotionally. Watching Mum so ill destroyed Dad to a point that we as a family thought that we were going to lose him too. Mum was very independent and my Dad relied on her to take care of their finances, their children and to provide emotional support. Dad has now had to sort things out for himself. He has lost about three stone in weight since Mum passed away; the last few years have taken a toll on him. There was one instance where Dad found Mum collapsed in their bedroom behind closed doors. She told him not to tell us about this incident and they hid the fact that she had had internal bleeding from us. They had spent three days clearing up their house because she thought she just had a bug. I have had to worry about both of my parents because of incidents such as this.
59. What Mum had to go through does concern me. I am so angry about the whole thing, it was wrong for Mum and for everybody in the family. I have tried to respect her wishes for privacy, but these things need now to be said. This has brought a lot of stress to our lives. I didn't know my Mum before she was infected with HCV. I need answers; I need to know why this happened and whether the doctors knew about it. Ignorance is not bliss and I want an explanation of this cover up; I want to know who is involved. I would like an apology for my Dad and my sisters and I would have loved one for my Mum. I want those to blame to acknowledge their part in this and admit that this was never my Mum's fault and to apologise. I know that it is not the fault of the nurses and that you cannot shoot the messengers, but it is the powers that be that should be accountable. It is wrong to put caring nurses under such

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pressure; someone has to be accountable and I do not want this to be brushed under the carpet anymore. This has affected me a lot and I am very angry. I want visibility as to why this happened. My anger is not a quick anger; it is a slow, simmering anger.

60. I am still coming to terms with my grief. The questions hanging over me have made the grieving process harder. I still feel stressed and under pressure; it feels like salt rubbed on an open wound. I cannot move forward as I want answers and I cannot get past the injustice of it all. My Mum was made to feel like this throughout her life and someone needs to acknowledge and explain why. I do not believe it is right.

Treatment/Care/Support

61. I believe Mum thought that it was not the 'done thing' to question doctors in the 1960s.
62. My family and I feel the doctors were trying to blame Mum for being infected with HCV when she was first diagnosed in 1999. The doctors asked Mum such things as whether she had ever stepped on a needle in the sand. Mum would have been upset by the doctors' questions and would have taken them as questioning her character. This would have been mortifying for Mum and my Dad was furious. My Dad was also a very private person. It must have been really hard for Mum to process what was going on. She was not the most confident of people. At work, she would get upset and take the blame even if she had done nothing wrong, being the type of person who would apologise for someone else's mistake. The doctors' questions would have knocked her confidence and she would not have felt comfortable in challenging them. Mum was not confrontational on any level. Rather, she would have taken it all in, then gone home and cried. She would have been mortified at the doctors' questions as she was always very private.

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Later in life, if I ever questioned the doctors about anything, Mum would get cross.

63. Whilst Mum was in hospital and only ten days before she passed away, I recall doctors questioning why she was there, without even reading her notes. As she was unconscious due to the swelling on her brain, the doctors just presumed that she was always like that. I had to alert them to the fact that I had had lunch with her the previous day and she had been fine.
64. Although it may have been the case that a suitable treatment was not available between Mum's first and second HCV treatment, I am concerned that her postcode may have affected what treatment was offered to her. She certainly did not have the money to pay for private treatment and I am concerned there was an element of ageism in her care, which meant that she was not offered treatments either because of where she lived or because of her age.
65. I thought Mum was made to feel lucky to be given the HCV treatment because she was always told that HCV drugs are expensive. In particular, she was told that her final treatment was worth thousands of pounds. This caused her to worry that the tablets she was carrying would be stolen from her on the train as she used to collect them from the hospital in person.
66. Mum would have notified anyone who was at risk of contracting HCV from her, such as her dentist. She hated being left until the end of the day for every appointment, including blood tests, colonoscopies and endoscopies for her varices caused by the HCV.

Financial Assistance

67. Someone told Mum about the Skipton Fund in passing. I do not know who it was. I don't think that the hospitals told Mum about it. I believe the Skipton Fund opened their doors in the late 2000s. My sister heard about the Fund on the news and told Mum about it. My Dad said that Mum did not initially want to make a claim. However she started to claim in 2005.
68. Mum always kept her finances private but I know she received a one off payment in June 2006 of £20,000 for those who did not fall within the haemophiliac category. She later received a second payment of £50,000 in February 2015. Additionally, she received a monthly payment but we are not sure when that started. I think it was around £1500, but was initially less than that. The scheme has changed more recently and she was receiving monthly payments of £1,230 in 2015.
69. As part of the application process, Mum had to get her doctor to sign the forms. She was referred to the consultant. The consultant requested a blood test be undertaken first. The doctor must ultimately have signed the forms as I know she received some money.
70. Mum was reluctant to apply to the Skipton Fund because she did not want to upset her doctor by asking for the forms to be signed. She was uncomfortable with the payment and believed she did not deserve it as it was a large sum. It caused her a lot of stress and she even visited my sister at her place of work because she was unsure about accepting the payment. Mum felt that she could not spend the money she received as she was concerned the Skipton Fund would ask for it back. The money sat in her bank account for fifteen months before she put it into ISAs. When Dad bought a car for Mum, she did not use the Skipton Fund money. She eventually gave some of the money to the family and renovated her kitchen. She left the remainder in her will. I think Mum

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was also concerned about what the neighbours and other people might think if she suddenly began to spend the money. In her eyes she was an ordinary working class person who did not have much money. If people noticed that she was spending more than normal, they might question where the money had come from and this concerned her. Mum spent so long worrying about not wanting to spend the money that she became too ill to use it. The money came too late.

71. I don't think Mum thought of the Skipton payments as 'hush money', but we as her family certainly do.

72. In my view, Mum did not receive enough money. I feel she should have been given a whole different life. She should not have had to worry about working full-time to pay her mortgage and provide for her family whilst she was ill. The money would have made her life easier. I do not feel she had any compensation or an apology.

73. We have had trouble in funding Mum's private healthcare. We have been to hell and back. This continues in that we are still in dispute with Mum's nursing home over outstanding fees. The costs were £4,500 per month. The South Cheshire Continuing Healthcare Team assessed Mum's savings, which included the Skipton Fund payments, and decided not to provide support. The situation over the last eighteen months has involved very little sympathy or support from the local authority, hospital, Social Services and the continuing healthcare team. It feels as if there has been one fight after another. Again, this is like pouring salt into an open wound. The South Cheshire Continuing Healthcare Team refused to reassess Mum, which caused her stress and my Dad to panic as to whether he could afford to keep their house. In this regard, the Skipton Fund payment was counterproductive and should not have been included in the South Cheshire Continuing Healthcare Team's calculations. The South Cheshire Continuing Healthcare Team spoke to Mum's family, social worker and nurses but

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failed to appreciate that there are different nursing needs for a person with both HCV and Parkinson's disease. They kept saying they had to assess 'what is up with her now, not what happened in the past', even though what happened in the past explained her needs at the time.

Statement of Truth

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

Signed GRO-B

Dated 27. 12. 2018