Witness Name: GRO-B
Statement No:WITN2475001
Exhibits: **WITN2475002-WITN2475005**
Dated: 1st April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. 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. In January 1979 I was diagnosed with rheumatoid arthritis resulting in multiple major joint surgeries, medical in-patient treatments and intermittent blood transfusions for rheumatoid arthritis related anaemia throughout the years.

3. In January 2010 I was diagnosed with hepatitis C (HCV) between 21-29 years after infection from receiving contaminated blood. I was successfully cleared of hepatitis C (HCV) by July 2011; 30 years after my 1st blood transfusion.

4. In December 2013 I received a hepatitis C (HCV) legacy diagnosis of hepatitis C induced Mild Cognitive Disorder (HC MCD) which was physically evidenced via an MRI by white matter ischaemic changes to the frontal subcortical and supratentorial brain area. The condition is permanent, there is no treatment available and it has damaged my cognitive abilities and my life, so the end of successful hepatitis C (HCV) treatment is not necessarily the end of permanent hepatitis C damage.

5. Due to my cognitive limitations, the content of this statement uses information gathered slowly, with great difficulty, over the 5 years since diagnosis. I want to voice my concern that I believe there may be a minority of other people, possibly already successfully treated for hepatitis C (HCV), who themselves may be unaware that negative changes in their cognitive behaviour may be due to this legacy condition.

6. I am frustrated and embarrassed at the length of my statement, but due to my brain limitations, I just cannot condense the following main points of my 2 different hepatitis C experiences any further; so I'm sorry for any repetition and too much information.

2.How Infected

1. I believe I became infected after receiving 3 blood transfusions for rheumatoid arthritis related anaemia between 1981-1988: July 1981 GRO-B GRO-B October 1982 GRO-B September 1988 GRO-B My last 1980's transfusion was 3 years before September 1991 from which time all blood used in the UK would be hepatitis C (HCV) screened.

2. From October 1989, a year after my 1988 transfusion I attended GRO-B GRO-B (" GRO-B ") GRO-B for nearly twenty years. As my rheumatoid arthritis was still aggressive I was regularly

seen in clinic by the Rheumatology team and was also well cared for on numerous occasions as an in-patient either post replacement surgery or for rheumatoid arthritis flares and medication reviews. One review was in July 1991 when I was started on Methotrexate (MTX) and monitored with regular liver function tests (LFT). Between 1996/97, the doctors became concerned as I had high Alanine Aminotransferase (ALT) levels, which they attributed to Methotrexate each time. When my ALT level was 3x as high as normal, doctors considered reducing the MTX dose but my ALT fell to half of what it was without altering MTX. My ALT then rose higher again despite reducing MTX so MTX seemed to have had no direct effect on my erratic ALT levels. As my LFT's had been persistently elevated since the previous year, I see from my notes that doctors strongly considered giving me a liver biopsy should my levels remain abnormal, but my ALT must have improved at that point as I never had the biopsy. If my ALT had stayed high for one more blood test or if they had considered testing for hepatitis C (HCV), doctors might have diagnosed hepatitis C (HCV) in 1997 instead of in 2010, between 21-29 years after my 1980's transfusions and importantly if hepatitis C (HCV) had been detected in 1997 I could have been treated at the time and been well clear of hepatitis C (HCV) before I received Infliximab anti-TNF biological drugs 11 years later in 2008. I only say this here because I wonder if perhaps, despite actually receiving various liver investigations over the years, any others in similar situations may have slipped through the hepatitis C net like me.

3. Whilst still at GRO-B and after a bad rheumatoid arthritis flare from late 2007, I finally received Infliximab anti-TNF therapy combined with MTX in February 2008, which I have seen make such dramatic changes to the lives of other rheumatoid arthritis friends. It was stressed to me that this combination gives the most effective outcome. It is worth nothing that I was not pre-screened for hepatitis C (HCV) prior to being given this strong biological drug. As a patient I don't know what NICE protocol was in February 2008 but I do believe that if NICE protocol had specified a hepatitis C (HCV) test prior to giving anti-TNF at that time it would definitely have been carried out at this hospital.

4. Initially, I had wonderful life-changing results. After just 2 weeks the 'headaches' at the top of my neck/the bottom of my skull which I'd had for 6 months, and for which we had previously discussed possible further C-Spine surgery, disappeared permanently. At 14 weeks I'd been told that I was just 1 point away from remission and in September 2008 doctors felt that I was responding very well after my 5th infusion, all having been given with long-standing MTX in place, and leading to an excellent pain free 7 months. This combined anti-TNF/MTX had worked better than anything since the start of rheumatoid arthritis 30 years earlier, completely turning my life around physically. Significantly, given my previous multiple rheumatoid arthritis replacements, I had 8 years surgery-free after this treatment. I moved away in September 2008 but for anti-TNF continuity purposes remained under the rheumatoid arthritis/anti-TNF care of GRO-B

5. Unfortunately my September 2008 infusion was cancelled due to raised ALT and, as in the 1990's, MTX was again withheld but this time for 6 months. In October my liver problems were under investigation and I was referred for an Ultrasound of the liver and gall bladder. I've since seen that in October 2008 doctors were deciding between using Infliximab alone without MTX until things improved. Otherwise they would consider another form of anti-TNF treatment altogether. As it was, doctors continued with Infliximab anti-TNF alone and although ALT appeared to be within normal levels by November, MTX wasn't considered again until March 2009 (after 6 months without it) when I myself asked doctors if it could be resumed.

6. Where my raised ALT was concerned, including both the 1990's and in 2008 a liver biopsy, liver ultrasound and gall bladder had all been proposed, yet a hepatitis C (HCV) blood test was not taken even though doctors were no doubt aware that many rheumatoid arthritis patients might have had anaemia related blood transfusions historically. As it was, the doctors didn't ask me if I'd had pre-1991 blood transfusions, but nor did it even occur to me that I wasn't already "fully covered" by the regular, monthly I think, LFT blood tests

I'd been having since 1991. In any case I know my doctors were trying to help me and as I am only a patient I have no idea how many blood/liver investigating options there are to choose from at this stage but just a year later, in December 2009, my new Rheumatology Consultant at GRO-B Hospital (and GRO-B) also suspended MTX when my ALT was raised, but in addition requested a hepatitis C (HCV) blood test. How was he able to pinpoint such a direct and accurate response?

7. Cumulatively without MTX, I struggled pain wise to last between my remaining Infliximab infusions at GRO-B I had my 6th infusion in November 2008 when my LFT's normalised after only 2 months without MTX but MTX was not recommenced. I received the 7th infusion, still without MTX, in January 2009 but by this time, and now 4 months without MTX, my rheumatoid arthritis was flaring. I still reacted very well to anti-TNF, but it wore off after 5 weeks without MTX leaving me 3 awful weeks to wait until the next infusion.

8. On 4th March 2009, my infusion was not allowed due to a urine infection but I asked if I could be restarted on MTX. On 11th March they noted MTX could be restarted as recent blood tests showed normal function well within the range (as it was in November). Before the letter had even been written I was admitted to GRO-B during the night of 9th March as an emergency case with suspected septic rheumatoid arthritis.

9. I was given morphine before they could even try to get me to the ambulance as every movement, even the paramedics just touching my legs to lift me off the bed and onto the stretcher, hurt more than I'd ever known; I really thought I was dying. Rheumatology, Gastroenterology and Microbiology teams were concerned regarding getting the right diagnosis and avascular necrosis and septic rheumatoid arthritis were amongst those considered. Eventually under the care of the Rheumatology Consultant, Dr GRO-B an MRI of the hips and fluid were taken and I was given a high dose of steroids and started on 6 weeks of strong antibiotics. I was very upset and frightened at the time that I

wouldn't be able to stand or walk again. I was still off MTX and now kept off Infliximab anti-TNF. I was in hospital for 2 weeks being treated for suspected septic rheumatoid arthritis and then followed a very slow recovery as I continued to be very ill at home which led to a serious rheumatoid arthritis flare. I was mostly in bed until my May 2009 appointment with my new consultant at GRO-B Hospital and I didn't fully recover until October 2009; 7 months later. On 21st April 2009, my rheumatoid arthritis care was permanently handed over to Dr GRO-B at my current hospital, GRO-B Hospital.

10. On 15th May 2009 I resumed MTX after an 8 month absence. My new Consultant discussed with me the possibility of restarting Infliximab, or an alternative anti-TNF, or Rituximab. I was happy to give Infliximab combined with MTX another try based on its initial success. On 22nd May 2009 I received my 8th Infliximab infusion which was 5 months after my 7th infusion that happened in the January. Dr GRO-B resumed the Infliximab anti-TNF, as started at my previous hospital, GRO-B in an effort to get me back on my feet rheumatoid arthritis wise as I was still absolutely struggling. This 8th Infliximab anti-TNF infusion was the least successful.

11. In July 2009, I was admitted to hospital for a blood transfusion for rheumatoid arthritis related anaemia and on 9th September 2009 Dr GRO-B decided to cease anti-TNF as it did not provide the degree of relief I had previously had. He then moved me onto Rituximab (RTX) which patients can only receive having first tried anti-TNF. Between 17th July and 14th September 2009 I received 3x infusions of RTX which is another biological drug. After 7 months of very poor health up to that point, RTX kicked in by October 2009. The life enhancing results were on a par with the 18 months remission I experienced which ended 6 weeks after the 1988 birth of our son and on a par with the first 5 months of successful Infliximab anti-TNF/MTX combination. At the time this was as good as I'd felt in 31 years since my rheumatoid arthritis symptoms first started, in August 1978, just 3 years before my first blood transfusion.

12. I believe that it will be significant that I had these strong biological drugs during 2008/2009 without being tested for hepatitis C (HCV). This is not the fault of my previous hospital who I know would have followed NICE protocol. However, having already been started on anti-TNF at my previous hospital, my treatment had picked up where it left off once I'd recovered from septic rheumatoid arthritis. My new hospital, GRO-B Hospital, had resumed with the further anti-TNF infusion and a course of Rituximab to tackle my destructive rheumatoid arthritis. However, once again, in November 2009 my ALT levels became raised and 9 months after my final appointment at GRO-B GRO-B I was finally tested for hepatitis C (HCV) in December 2009 by my new consultant Dr GRO-B at GRO-B Hospital.

13. My hepatitis C (HCV) blood test was requested by Dr GRO-B on 4th December 2009 as 'recent liver test was elevated.' Within just months of becoming his patient, Dr GRO-B suspends MTX as a precaution but at the same time requests a blood test for hepatitis C (HCV). My family will forever be grateful to Dr GRO-B.

14. I received the diagnosis of hepatitis C (HCV) ab positive on 28th January 2010. Dr GRO-B rang me to say that the blood test confirmed I had hepatitis C (HCV) and MTX was given the all clear. He also tells me that he would not have recommenced me on Infliximab in May 2009 or started me on Rituximab if my hepatitis C (HCV) had been known about. He tells me that it would not be safe to have further treatment with either until the hepatitis C (HCV) is eradicated and that even if the hepatitis C (HCV) if successfully cleared, he said that I would still have to be 18 months clear before I can re-use those treatments to treat any future rheumatoid arthritis flare. So in fact, for a period of 3 years, from hepatitis C (HCV) diagnosis in January 2010 to the 18 month post treatment all clear in January 2013, I could not have been treated with strong biological drugs should I have had a flare as the use of Infliximab or Rituximab could allow hepatitis C (HCV) to re-activate.

15. On 9th February 2010, the Consultant Gastroenterologist, Dr GRO-B, who would be in charge of my hepatitis C (HCV) therapy, wrote to my Rheumatology Consultant Dr GRO-B Exhibited before me at WITN2475002 is the letter which discusses my treatment and Dr GRO-B notes that in his department patients are always routinely screened for hepatitis C before receiving anti-TNF dated 9th February 2010. I would like to know if, by 2009/2010, hepatitis C pre-screening had now become NICE policy or was it just that this department of this hospital, GRO-B Hospital, has its own additional stringent levels of pre-testing prior to giving anti TNF drugs?

16. I appreciate everything my Consultant Dr GRO-B staff at GRO-B Hospital and its local sister hospital (GRO-B Hospital), my GPs and all related multi-disciplinary teams have done for me particularly throughout my 48 week hep C treatment. On 8th February 2010 Dr GRO-B advises the following 'can restart MTX now we know Hep C is responsible for the raised ALT markers.'

17. I had treatment for hepatitis C (HCV) between August 2010 and July 2011. My supportive liver nurse explained that I had Genotype 1 hepatitis C (HCV) which meant the longest treatment at 48 weeks and the lowest chance of arresting hepatitis C (HCV) at 45-50% plus a 25% chance of a recurrence which then makes it untreatable. We discussed brain fog or 'scattiness' which I'd had for some years without knowing its name. Amazingly, my high viral load fell to less than 15 at 3 months. The 48 week treatment was awful with cumulatively worse very bad side effects but the all clear was wonderful! My successful treatment ended 30 years to the month since my first blood transfusion and that should have been the end of my hepatitis C story and my statement.

3.Other Infections

1. Unfortunately, just over 2 years later in September 2013, and responding to my family's concerns about my deteriorating cognitive abilities, my GP referred me for an MRI of the brain to investigate what she thought might be

'some form of dementia.' So just 2 ½ years clear of hepatitis C (HCV), in December 2013, I was diagnosed with a hepatitis C legacy condition of hepatitis C related Mild Cognitive Disorder (MCD). This was MRI evidenced and linked to the hepatitis C (HCV) infection impairing cognitive function as physically evidenced by visible minor white matter ischaemic changes to the frontal subcortical and supratentorial areas of my brain. This is a permanent condition with an unknown prognosis and no treatment is available.

2. In clinic to discuss my hepatitis C MCD diagnosis, my Consultant Psychiatrist, Dr GRO-B, acknowledged my inefficiencies in memory, difficulties multi-tasking, compensatory changes in keeping with mild subcortical disease, word finding difficulties, losing track of what I was saying, associated lack of confidence and my family's concerns about cognitive functioning particularly in the last 5 years. Exhibited before me at WITN2475003 is a letter from my GP to Dr GRO-B dated 10th September 2013. He advised that prognosis was difficult to predict as not enough is known and that as I was his only patient with this diagnosis, I should do as he'd done, and 'look for further information and advice about hepatitis C (HCV) and cognition through internet searches.' He explained that white spotting on my brain signals dead areas so during conversations when my electrical thought messages try to get through they sometimes meet a dead end/white spot and have to find another way, taking a longer time or they struggle to find a way at all until I receive verbal prompting to help me make a connection within the conversation I'd been having.

3. My hepatitis C MCD is a 3 layered process which spans physical and mental changes: I have Hepatitis C-related permanent physical ischaemic changes to the white matter of the frontal subcortical and supratentonial areas of the brain which cause changes in cognitive behaviours such as worsening short-term memory loss affecting mainly decision making, efficiency of information transfer, lack of confidence and consequent loss of ability to be responsible in certain areas of daily life. This in turn causes the side effect of anxiety, an awful dread I wake up with every morning and which I've needed GP-guided support to try to manage. There's no treatment available for this permanent

condition, but prompt referrals from my Consultant led to my receiving excellent support from my GPs and the spot-on Memory Advisory Service whose list of everyday practical tips is invaluable.

4. Otherwise there's no guidance or peer group support and in particular very little medical acknowledgement or apparent realisation that this hepatitis C MCD (or a potential associated neurocognitive disorder) condition has now also been diagnosed as being received as a legacy condition through contaminated blood. This means that no medical professionals, including my GPs and memory advisor, and others who I have since had cause to mention it to in the course of listing my medical conditions ahead of new treatments or operations for my rheumatoid arthritis, seem to have heard of the permanent legacy HC/MCD, MRI-confirmed condition. Exhibited before me at WITN2475004 is a letter between my GP and Dr GRO-B dated 2nd July 2014 regarding my MRI results. However, I need to know for a fact that I am giving HCPs the correct cognitive diagnosis and have not misunderstood, precisely because of my MCD, what was explained to me in clinic. I wanted further professional reassurance that I was correctly giving a valid, acknowledged diagnosis of my condition. In 2014 I had found a report on hepatitis C (HCV) crossing the blood-brain barrier to infect and actually damage the brain (Maurier 2010) but 2 years later in February 2016 I returned to the Internet adding the words 'white matter ischemic changes, subcortical' directly from my own diagnosis and was shocked but amazed to find recent research apparently confirming physical white matter changes on the brain definitely being linked to hepatitis C (HCV). Four extracts of my research are: 'abnormalities in the frontal white matter ... suggestive of frontal subcortical pathway involvement similar to the involvement described in HIV infection' (Irwin/Terrault 2008), 'Only cortical and sub-cortical areas are involved in HCV associated neurocognitive disorder (HCV AND) (Monaco, 2015) and 'HCV triggers an irreversible neurodegenerative brain damage ... These evaluations should be associated with MRI' (Solinas 2015). The final extract being 'Mild Cognitive Disorder has been included to expand the concept of White Matter Dementia by proposing a precursor syndrome related to early white matter neuropathy ... white matter is critical for rapid and effective information

transfer ... the dominance of grey matter as the locus of higher function has strongly directed neurobehavioral inquiry to the cerebral cortex, while white matter has received less attention.' (Filley 2012 – but this is hopefully looking too far down the wrong road)

5. My Psychiatric Consultant, Dr GRO-B , approved this research in November 2017 and I am extremely grateful to him for his support. He believes that this condition is probably under-recognised as patients in similar situations attribute their symptoms to other factors and that it is probably the minority of patients who will suffer with hepatitis C associated neurocognitive disorder.

4.Consent

1. I do not believe I was tested on without my consent or knowledge or for the purposes of research.

5.Impact

1. Between 1996/97, relatively soon after the introduction, in September 1991, of hepatitis C (HCV) screening of all bloods supplied in the UK and at a time when rheumatology doctors were very likely to be aware that many rheumatoid arthritis patients would have had anaemia related transfusions pre the 1991 all clear, concerned doctors considered a liver biopsy to explain my raised ALT but just at that point my ALT returned to normal. If a hepatitis C (HCV) test had somehow been considered I could have been diagnosed and treated for hepatitis C (HCV), and therefore safe to receive anti-TNF/RTX drugs in 2008/9 without risk of aggravating underlying hepatitis C (HCV); which in turn might probably have saved me from permanent legacy HC MCD following up to 30 years of long-term existence of untreated hepatitis C (HCV) in my body.

2. Similarly in 2008, at GRO-B when my ALT level became raised during anti-TNF therapy, MTX was removed for 6 months while other further investigations of the liver, including ultrasound of liver and gall bladder, still

did not include a hepatitis C (HCV) blood test. Yet at GRO-B Hospital, when raised ALT occurred following biological drug infusions in 2009, just a year later, as a precaution MTX was suspended but crucially a test for hepatitis C (HCV) was also carried out. Within days of being diagnosed I'd written to my Rheumatology Department to say I was worried there would be other long term and regularly seen patients like me who unknowingly had undiagnosed hepatitis C (HCV) and that is still my worry. They may even have had powerful hepatitis C contra-indicated biological drugs for their original chronic condition. Even at this late stage, a simple clinic questionnaire in such departments could identify pre 1991 blood transfused patients who have yet to be tested for hepatitis C (HCV); and perhaps just 2 questions would be enough, 'Did you ever have a pre-September 1991 blood transfusion? And, if so, have you since been tested for hepatitis C? Hepatitis C (HCV) testing before receiving biological drugs could yet pick up others like me and an MRI could validate this legacy HC MCD condition.

3. Regarding the suspected septic rheumatoid arthritis in March 2009 I believe the clash of powerful anti-TNF with my underlying hepatitis C (HCV) could possibly have been a contributing factor to my illness. We, my husband and I, both thought I was going to die and it was a terrible time.

4. I was treated for my hepatitis C (HCV) between 2010 and 2011, but the immediate concern for me was that my son had been born shortly before my 1988 blood transfusion, so he and my husband were promptly tested and thankfully both were clear of the virus. During my 48 week treatment, exposure to strong drugs including Interferon and other drugs to counter act side effects meant problems kept building cumulatively. In particular I remember 3 lots of antibiotics for teeth and jaw; and also nausea and rashes; rheumatoid arthritis anaemia related blood transfusions even during my treatment, and other serious matters. We had to cancel a low key holiday due to my poor health and, towards the end, my hospital notes show it was doubtful I could finish the course due to the degree of cumulative side effects of the drugs, but I did; by the last day of the treatment I was under 6 stone and quite skeletal. At the start the nurse had told me relationships could be

under real stress as treatment can make behaviour psychotic. I thought I'd be alright as I was used to operations and treatments so didn't mention it to my husband, but I should have done as my moods and behaviour noticeably altered, and while my husband had always been completely supportive rheumatoid arthritis wise, he found the mental changes in me much more difficult to cope with, which caused an unfamiliar stress between us.

5. The 2013 diagnosis of permanent cognitive damage to my brain has had a massive, and still growing, impact on my life and relationships. Everything in this statement has taken me the last 5 years since diagnosis to write. I used to be organised but by summer 2014, only months after my eventual diagnosis, my ability to be responsible for others was affected especially when trying to keep up in the 'real world' with official or instantly responsible situations. Cognitively I was no longer able to continue with work responsibility as a voluntary GRO-B or communal responsibility on the management company where I live, nor (later) family responsibility being co-attorney for my Dad's already activated Power of Attorney. My combined MCD traits – difficulties with short term memory and decision making under pressure, with getting the 'gist' of certain conversations, and with scanning, prioritising written information especially formal or urgent, and frequent blips in regards to dates, times and calendars - left me inadequate when it mattered.

6. Family and friends used to come to me for advice and written help but not any more! When managing important paperwork I'm now working on a cognitively restricted amount of information that I can absorb in one go. I keep getting realisations of the whole picture later, over time, in dribs and drabs. The same for immediate decision making situations 'Sorry, I can hear what you're saying but can't quite get the gist, so do you mean ... or ...?'

7. Even when at home and not under pressure I would forget if I'd taken my medication (I've now had a blister pack for many years) and as I attend 2 local hospitals I would go for my appointment at the wrong hospital or on the wrong day. My husband goes with me now to help me to remember the outcome of

conversations at my hospital appointments. As this statement shows I give too much detail in conversation and in writing; this is like an illness in itself. Friends and family notice I over worry about small details and need to give every bit of information. Despite all of this I have a very loving supportive circle of family and friends.

8. A further huge impact of this whole thing has been the amount of time I've spent writing and writing at the laptop; trying to explain my diagnosis and how it has affected my abilities, my relationships and my life, and how I am concerned there may be others as yet undiagnosed with this condition. Precisely because of the cognitive restrictions it causes, I now take forever to produce something clear and concise and covering all the main points I need to say, without repeating myself and something I could never manage now in a face to face conversation. Instead, in trying to give every last detail I duplicate and multiply paperwork which is like an illness in itself. This whole process of creating a mountain of paper, of shredding, then struggling to compress all the important bits into something clear and concise is ridiculous and anxiety-making, but I now cannot hold onto key details of complicated paperwork otherwise. The responsibility of getting this statement right has been too much for me and my brain as writing it involves precisely all the cognitive issues I now have difficulties with. This has meant my statement going back and forth many times as I panic about what I've added or deleted each time. It has worried and depressed my husband to see me going back to this all the time, and has often stopped me seeing friends in trying to get paperwork done by a certain date.

9. This is how I've got information together to write to the Department of Health to ask if they acknowledge this condition (a non-answer), to reply to every infected blood consultation, to complete the Special Category Mechanism (SCM) form assessing how much you had been affected by contaminated blood, to complete feedback re the ease of use of the SCM form, and finally to write this statement. Each of these tasks came from a slightly different angle which meant paperwork had to be tweaked to fit appropriately resulting in more hours of retyping. I would create new files for slightly different variations

of answers needed then lose track and have to read, word for word, the answer for the new task against the sheet I'd used for a previous consultation. My brain! I just shouldn't be doing this. Not good for my rheumatoid arthritis hands, arms and vulnerable neck, definitely not good for my brain – which is the whole point!

10. The SCM required examples of how you were affected on a daily basis. I wanted to explain my HC MCD thoroughly as it has changed my life, and the me I am now, in ways physical rheumatoid arthritis never did. On the plus side, some of what I had previously written has saved me time and has helped me explain my legacy condition here in my statement. In my requested feedback on the SCM form I explained that my condition has both physical and cognitive aspects. It is caused by hep C and is physically based, and it also damages and limits cognitive abilities. It is permanent and possibly (probably in my experience) progressive. I suggested that if the form is ever revised, they could include a brief description of this MRI evidenced legacy HC MCD brain condition somewhere on the form so that others might identify with it if they are similarly affected, as they have already done with another condition. I stressed that I was definitely not comparing my condition to the specific and serious pre-listed causal conditions in a separate section of the form.

11. After all this, and at the point where I can now pass this message over and leave it to others to decide if anything needs to be done or not, I have just run out of steam and even question why I have written all of this. I realise and feel embarrassed that I have gone into too much personal detail in this statement, but I did it so that IF there are others affected in the same way, perhaps they will identify with many of the cognitive behavioural limitations, and decide to follow up with their GP. I have spent so much time trying to raise this issue, but it has only now really struck me that as my Consultant wrote, it is probably only a minority of people who will have this condition. Exhibited here at WITN2475005 is the letter from Dr GRO-B dated 24th November 2017. I realised that they'd probably have to have had, and survived, undiagnosed hepatitis C (HCV) for decades, like me, then probably

had a specific event, like taking biological drugs to treat a chronic, possibly auto-immune, pre-existing condition to have finally tipped things over into causing actual and permanent physical damage to the brain. So perhaps, after all this, there will not be many of us at all – but then that would be a good thing. In any case, I did what I thought was right for any others like me, but after this statement I never want to talk about this again which is why I hope my request for anonymity will be respected.

12. My cognitive issues have changed me, I now feel mentally as well as physically vulnerable for the future. My husband helps 'carry' me mentally, not just rheumatoid arthritis-physically now, and so his responsibility has increased. I'm still me to my family and friends but a noticeably less confident, less competent version as I've gradually been losing more of my old mental self. I can be frustrating for others and myself to live with. I can't help others as I used to and I can't take on any responsibility. My life and the lives of those closest to me are hugely affected by the cognitive limitations of the permanent condition and my 'mild' cognitive disorder certainly does not feel mild to me.

13. I have anxiety on waking every morning, a feeling of dread, of something bad coming and it can feel scary and suffocating. Permanent MCD alone has definitely changed my life but its possibly degenerative prognosis makes me fearful for my future. All these examples define who I am now and I feel far away from how I used to be..

14. I have never suffered from any educational effects, but I did have to give up my four hours a week voluntary job as an GRO-B which I loved, in July 2014, due to my hepatitis C legacy brain condition.

6.Treatment/Care Support

1. Throughout my hepatitis C (HCV) treatment the 2 hospitals I attended GRO-B Hospital and GRO-B Hospital, GRO-B were very

supportive to me and I received excellent care from the staff. I was provided with appropriate information and encouraged to ask any questions.

2. I have never suffered any difficulties in accessing treatment or support because of my hepatitis C (HCV). I just wish my hepatitis C (HCV) had been diagnosed pre 2008 when I received biological drugs so that perhaps my legacy brain condition might never have taken hold.

7.Financial Assistance

1. Up to April 2018 I have received £ GRO-B from the Skipton Fund/ GRO-B From the Skipton Fund I received the following amounts which they informed me I was entitled to, I did not approach them. On diagnosis/treatment of hepatitis C (HCV) in 2010, I received a one-off lump sum of £ GRO-B In 2016 I received £ GRO-B and in 2017 £ GRO-B As of November 2017, I received money from GRO-B In 2017/18 I received £ GRO-B in 2018 £ GRO-B SCM (Special Category Mechanism) backdated to 2nd October 2017 plus £ GRO-B as SCM new payment plus £ GRO-B covering April – September 2018. Continuing from April 2018 I receive an annual payment of £ GRO-B until further notice.

2. Apart from completing the SCM I have not applied for financial support. I always thought that discretionary payments were for people who had lost a family member. I didn't realise that we may have been eligible for income top up as immediately following my permanent hepatitis C legacy brain diagnosis in December 2013 my husband gave up work 8 years early to support me.

3. Until last year I wasn't aware of other assistance that may be available to me but GRO-B sent out household top-up paperwork to see if people were eligible. I missed the deadline for it be backdated to April 2018. I finally posted it on 6th March 2019 as up until then I've been so anxious to get everything ready to help me complete my statement. It's all been too much paperwork, anxiety and stress for my brain.

8.Other issues

1. In August 2017 the Inquiry team had stated, 'It is vital all those affected have their voices heard,' and asked for thoughts of what should be included in the scope of the Inquiry. I voiced the fact that, 'the end of successful treatment for hepatitis C is not always the end of MRI evidenced hepatitis C damage. In some cases, hepatitis C can leave a permanent negative health legacy even after successful treatment.'

2. I believe more awareness is needed by medical professionals and hepatitis C (HCV) patients themselves of the possibility of the hepatitis C related MCD legacy developing, despite successful treatment to clear hepatitis C (HCV). Some of those affected may even be unaware that negative changes in their cognitive behaviours mean they may have this condition. I feel that being very long-term undiagnosed before receiving hepatitis C (HCV) treatment may be a significant factor in itself; and if combined with biological drugs maybe more damaging, which is why a simple clinic questionnaire, even at this late stage, might still help some people. I was lucky in that my concerned family made me go to my GP. All of us that have it will be in need of informed support on diagnosis. Perhaps everyone should receive a brain MRI post hepatitis C (HCV) diagnosis. I want to raise my concern that there are probably others as yet unaware of their HC MCD condition which can be validated by an MRI.

3. I have never engaged in previous litigation related to infected blood products, and I don't think I have any other documents which may be relevant to the Inquiry but because of my brain I worry that I may have forgotten something.

Statement of Truth

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

Signed GRO-B

Dated 29.03.2019