

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3660001

Exhibits: WITN3660002 - 005

Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

**Section 1. Introduction**

1. My name is GRO-B of GRO-B  
GRO-B My date of birth is GRO-B I have been married to my husband for GRO-B years, and we were together for several years before this.
2. I make this statement supplementary to that of my husband, GRO-B: H  
GRO-B who was infected with Hepatitis C (Hep C) as a result of receiving contaminated Factor VIII (FVIII) concentrates. My husband has also produced a witness statement to the Inquiry, GRO-B
3. This witness statement has been prepared without the benefit of access to my husband's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

**Section 2. How Affected**

4. I wish to rely on part of my husband's statement for this section.

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5. I met H when I was GRO-B: H and he was GRO-B: H at a pub quiz and we were both working fulltime in a clerical capacity. We have no children or close family members.
6. H has severe Haemophilia A and I believe he was diagnosed at a young age. Prior to our marriage I was obviously aware of his haemophilia, and the necessity for his Factor VIII (FVIII) injections. Although he had some mobility issues, we had a good social life and took part in as many interesting pursuits as we could manage. We particularly enjoyed visiting Stately homes and driving around the countryside, taking in the scenery it afforded.
7. During these years however, the spectre of HIV had begun to surface and in due course my husband informed me that he had received a negative test result. He was unaware he was being tested at the time (according to medical records obtained recently, further tests were subsequently conducted at intervals, including just after our marriage, of which I was also unaware). Although he was relieved, it was something I felt was always at the back of his mind. Unfortunately from that moment on it was permanently at the front of my mind and it was then that the first signs of my own anxiety began to emerge.
8. Even when FVIII began to be heat treated and was supposedly 'safe', I did not have much confidence or faith regarding it and was perpetually worried each time my husband had to inject himself. Fortunately he was not exposed to HIV, but I feel this was due to good luck rather than good management, and since finding from the medical records that whilst receiving these products, surreptitious HIV tests were still being conducted against specific treatment batches, my misgivings may have been justified. The stress of this period eventually led me to be unable to cope with my demanding full-time employment but, as my husband was still working for the Civil Service in the job he had held for 15 years, it was decided that I would become a full-time housewife instead, partially also for the benefit of us both, as by this time my husband was finding his life/work balance more difficult, due to tiredness and more bleeding episodes. We used to joke that being married did not agree

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with him, but realised now that the Hep C that he was unaware that he was carrying, was probably beginning to take its toll.

9. In [GRO-B] we decided to take a holiday abroad together for the first (and last) time. Unfortunately while we were away I became unwell. In time over the following years I gradually went on to develop agoraphobia, muscle weakness and chronic fatigue from which I have never recovered and which I firmly believe has been exacerbated due to the unrelenting stress of the situation with [H]
10. It was around this time that rumours of the 'new' infection, Hep C began to circulate and although we were worried, neither of us wished to confront a firm diagnosis, having only recently shed the previous concern of HIV. Also from what we understood, potential remedial treatments were unavailable, unsuccessful or overly harsh.
11. Over the next few years my husband was tiring more easily and quickly, was stressed and experienced more bleeds which were negatively affecting his severe poly-arthritis joint condition. He was having difficulty managing his workload as an [GRO-B] for what was then known as the [GRO-B] and he was taking considerable time off work. Eventually the situation became such that by mutual agreement with his employer it was decided in [GRO-B] that he would take early retirement, which entitled him to a small pension. We thought at the time that regrettably his haemophilia had finally caught up with him, however, what part the Hep C played in this situation I can only now speculate.
12. By this time I had become virtually housebound with agoraphobia and chronic fatigue, (for which I underwent some psychological counselling from a community nurse, to no avail) so we found ourselves marooned in our first home that we bought together with the requisite mortgage – (carrying no life insurance or mortgage protection) a first floor flat, where neither of us could manage the stairs safely anymore.
13. We very reluctantly decided that we would have to change our living accommodation knowing what an ordeal a move would be and managed to

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find a one bedroom bungalow close by. It was in a very poor state of repair, but it was all we could find and afford as the mortgage would need to be somewhat increased again without life insurance or mortgage protection. This was a decision we soon came to regret but were forced to endure for the next 20 years.

14. One of our first visitors called unannounced shortly after we had arrived, a Nurse Counsellor from my husband's Haemophilia Centre to try and condescendingly 'persuade' him to take a Hep C test, as he was still unwilling at that time. We have always resented this unwarranted, intrusive and invasive visit, which in our opinion was purely to satisfy the hospitals agenda – my husband was quite capable of deciding his own fate and any decisions on this matter should have been his to make, (the patient should always have a choice not an obligation, as it appeared to be presented) and accepted as such – in any event, he chose to decline until a time of his choosing, which did not, I feel, meet with approval.
15. By **GRO-B** my husband's Haemophilia Centre had become quite insistent that he take a Hep C test to which he agreed. This was conducted via our local GP. It was a positive result. Once the threat became a reality, my husband immediately embarked upon an healthy lifestyle regime, conducive to promoting as healthy a liver as possible and taking some control over his condition the best way he could, including natural health medicines prescribed by a reputable well known practitioner, which he follows to this day. This has proved expensive but worthwhile in our opinion.

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

16. In **GRO-B** an unexpected letter arrived with information regarding my husband and his potential exposure to vCJD, related as casually as if it were the common cold. We were astounded, angry and disheartened, it was another blow and the thought of what would be next crossed our minds.

### **Section 4. Consent**

17. I wish to rely on my husband's statement in relation to this section.

**Section 5. Impact of the Infection**

18. Although the result was the expected outcome, we could not avoid the emotional upheaval the diagnosis caused, and our attitude towards life changed forever from that day onwards, becoming totally negative as a result.
19. My husband began to worry about how we would both manage if his health declined significantly, alongside my own health situation. Where we lived was not near facilities should he become too ill to drive. Having always been told by his relatively well off adoptive parents that should he need help he only needed to ask, although always preferring to be independent, perhaps due to attending a boarding school for the handicapped, far from home, aged 11, he decided to enquire whether they could assist with a potential move to a nearby village to a suitable property which had all the amenities nearby as he would need to increase the mortgage yet again, which was a dilemma and a risk. Unfortunately his parents took the attitude that he was overreacting to his diagnosis - obviously oblivious to the facts, they deemed it was nothing to be concerned about and unimportant, as he would only 'be tired and go yellow' and besides they were financially committed to his sister, her children and partner. My husband felt they were totally disinterested and did not pursue the matter any further but he felt terribly let down. We became completely withdrawn, isolated and detached, which then caused ill feeling amongst his family members who may have felt rejected and as a result relationships became strained or severed completely. We have very limited contact with my own family due to distance and circumstances. Subsequently we have found ourselves without any support, which has led us to an ingrained obsession with self-reliance. Assistance would mean failure to cope, a slippery slope we cannot allow ourselves to contemplate.
20. In 2003 I became officially what I had been for many years, a full-time carer to my husband (I receive £9.44 per a day for this) which continues to-date. I do worry that if due to my own health concerns I should predecease him, what would happen, as I am fully aware he could not cope alone, which would

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mean either carers in to assist should they be accessible, (which he would hate) or some kind of sheltered accommodation, which is also unappealing.

21. As stated in my husband's statement, in 2004 my husband received the Skipton fund ex-gratia payment, which although a welcome development, was soon swallowed up on debts and other essentials, including a funeral plan as by this time he had not worked for 10 years and we lived on benefits and his small works pension, so it was a short lived reprieve, then a quick return to financial jeopardy.
22. Despite living frugally, it was commonplace to make a food shopping list, only to calculate the cost and then remove several items as we could not afford them. At one point we decided to sell some commemorative coins we had since our youth and once sold a ring that belonged to my husband to a 'gold for cash' buyer at the door. My husband took to wearing my late father's clothes and still does to this day, I am still wearing my GRO-B year old mother's hand me downs.
23. I particularly recall one Christmas that we had a big debate over whether we should get some Andrex quilted toilet roll instead of Sainsburys Basic in the unlikely event anyone should call unexpectedly. We decided against it in the end – too extravagant!. It sounds humorous now but it wasn't really, it was just an example of how we lived.
24. Christmas dinner was something basic, we had a pair of slippers and a diary each; we still do this now. It's a habit we can't shake off, even though things are not as dire now, the fear of poverty still holds us captive to a degree even today. We constantly struggle to spend money on what may be considered non-vital items without feeling worry, guilt or stress over whether we have done the right thing even though it is rarely anything over expensive. We are at war with ourselves continuously, especially due to the knowledge that whatever financial assistance we presently get may not be permanent.
25. In 2005 the recombinant FVIII became available after a delay due to my husband's age, which meant more worrying and waiting. This was accompanied by further stress due to a situation which had developed

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regarding my husband's supply of treatment from the Haemophilia Centre as detailed in his own witness statement. This matter finally came to a head in 2007, with the ultimatum of capitulation to demands, or cessation of treatment supply (for a severe haemophiliac), which necessitated a change to the more local Haemophilia Centre he attends to date, where he receives wonderful treatment, care and respect in contrast to his previous experience, which in my opinion consisted of petty, arrogant and inconsiderate behaviour considering all the facts, including that it was at that centre he had received the infection.

26. In 2005 I became eligible to receive DLA low rate care and mobility in my own right which has continued to date (£6.62 per day), but I am due for an imminent PIP claim assessment, which has caused me great stress and anxiety, especially as I am doubtful as to whether it will be successful. I do not yet receive a State Pension, due to the change in women's pension age, and will have to wait until I am 66.
27. In 2008 my husband embarked upon his first round of AV Therapy, a 48 week course consisting of Pegylated Interferon and Ribavirin, which inevitably resulted in all of the well documented side effects, which to a lesser degree remained after cessation of treatment, (he went on to develop a leg ulcer which took over a year to clear and is now at risk of more). The treatment failed – I thought the results were a mistake and that he had someone else's notes by accident, but this was not the case. It was a severe blow for us both, he was in a very poor state and there was no other treatment available at the time. We became even more disheartened, defeated and disengaged. One of the worst aspects for me was the deterioration in my husband's personality, which changed dramatically - he became at times self-absorbed, indifferent to me and with my own state of health, the condition our house was in and living conditions, our home in general and our financial situation, especially when undergoing a bleeding episode or when his arthritic condition was being particularly troublesome. Perhaps understandably he became uncooperative and argumentative, which has continued over the years. Consequently our lives seem to take on a trench warfare mentality a lot of the time and everything is a battle of wills – it has become the norm and we know no

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different now, but we are still a partnership and have learnt to accept things the way they are.

28. By 2011 our house had fallen into dilapidation. We were having to continuously contend with widespread damp and mould, there were ants and slugs and the back boiler central heating system had been deemed unsafe to use by the gas engineers. Half of the radiators had burst and so were unusable, so we had very little warmth and resorted to using a small oil filled radiator and a heated clothes airer as a last resort. As we realised this could not continue indefinitely and the situation was leading to further deterioration to the fabric of the house and was detrimental to our health with the financial assistance from my mother (by this time a widowed, registered blind, income support pensioner living in sheltered accommodation who was very concerned about our living condition and wanted to help despite us having reservation about accepting), we had fitted a small electric boiler (cheaper to buy and install but very expensive to run), and kept it's usage to a minimum – also, as a result, we had the water heating element disconnected to save money and subsequently lived for three years with no running hot water.

29. Unfortunately while all this was occurring (and whether it emanated originally from the condition of our property and car I am uncertain) there became a problem with a new resident nearby. There was an unhidden contempt shown regarding the fact that my husband was not in employment (and presumably a burden on hard working taxpayers such as themselves?) the phrase “surely you are too young to be retired yet” was voiced and an unpleasant atmosphere developed. This eventually became an intolerable situation which escalated to the point where we felt the need to divulge what was occurring to our GP as our health was suffering considerably – our stress levels were off the scale (my GP offered to arrange for some psychological support for me, but I held this in reserve) and also our Solicitors, as we felt we may need legal advice, and/or assistance should things advance further. Both of these professionals, hold all relevant details and can verify what was then occurring. Their immediate advice at the time ran along the lines that, on no account should my husband divulge the nature of his illness, that the police should be informed should a situation arise that warranted it and that we



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should consider moving house if at all possible. In desperation my husband felt he had no choice but to once again (12 years having elapsed since his previously failed overtures) approach his parents for financial help regarding another property in the next village, again near to facilities and which would be an ideal place to finally settle in for whatever time remained. Having explained the full details of the overall situation to them, it was agreed that some cash could be released, as there would still be mortgage considerations etc (so to speak his inheritance in advance) and plans commenced to action this, much to the consternation of his other family members who had, until that moment, continuously been the sole recipient of unconditional financial support. Regrettably, seven months later, on the day of signing the relevant paperwork, his mother reneged, citing that the arrangement would be "unfair" to others, and strove to make it appear that my husband had manoeuvred her into a situation she was uncomfortable with, rather in my opinion than expose the real truth regarding the family dynamics, in the process ruining his reputation with his own solicitor (this character assassination hit him particularly hard and he took appropriate steps to rectify this implied lack of integrity – subsequent future events to which our solicitor was privy in time exonerated him of any suspicion of wrongdoing). As I perceive their characters to be, the thought that he might die prematurely and their money be "wasted" on him, or worse still that I could end up being the unworthy recipient of this largesse may also have been a deciding factor.

30. All of the above events could potentially have been avoided had my husband been in receipt of some kind of external financial support. I will never, as long as I live, forget that day, his face when he came home and the effect this utter betrayal had on him then and in the years to come. From that moment onwards he severed all ties with this "family", it was obvious there was no relationship to preserve. As it transpired a short time later the family, enmasse, moved out of the area/county, without providing a forwarding address which perhaps speaks for itself.

31. It was still our intention to move house, and this became our mission (fortunately the issue with the resident resolved itself as they subsequently left the area, but other concerns remained, and the property had become indelibly

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linked in our minds with traumatic events). Over the next four years whilst the house was on the market we strove with yet more financial assistance from my mother to try and patch up the house to a tolerable standard. We came to know our handyman quite well to the extent that he even went so far as to not only offer us the use of his seaside holiday caravan as in his opinion "we needed a break", but also suggested that he could always lend us some cash from his savings if it would help us. We of course declined, with much thanks, but I always felt shame that he felt the need to pursue those avenues. The estate agent almost became a fixture for the duration as we thought it prudent to have them show potential buyers around to avoid any chance of awkward questions. Unfortunately we could not avoid the humiliation of over hearing the many comments made about the condition of the property (one viewer even refused to set foot inside, the outside being off putting enough despite our best efforts) and that it needed to be "gutted".

32. In 2013 my husband's 'Invalidity Benefits' changed to ESA. This involved the requisite provision of relevant documentary evidence and overall caused much anxiety. We had by this time taken to using a "foreign" Post Office for DWP letter posting due to the shame and stigma of being seen as "benefit scroungers". Thankfully his claim was passed and he was placed in the permanent Support Group.
33. I also made some enquiries to the Department of Health (DoH) concerning the overall situation regarding infected blood. I exhibit a copy of their reply at **'WITN3660002'**.
34. It was also at this time that due to my husband's level of income, he became eligible for a top up from the Caxton Foundation, alongside the availability of grants. We chose not to apply for help with the property, this seemed wrong as we were not intending to remain there.
35. In 2015 we finally sold the house for £14,000 less than comparable properties nearby, due to its condition. This left us with yet another dilemma. The markets having changed over the years, (we had pursued, many opportunities, only for them to fall through over the intervening period) the

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only property available at short notice was a house, which was not ideal, nor in the perfect location, but a better option than where we were and it would require an increased mortgage and deposit. My mother once again stepped into the breach, parting with a considerable chunk of her life savings – she was adamant we accept her help, as she most of all had been privy to the various hells we had gone through during the years. We very reluctantly agreed, and have always regretted having to resort to it, but felt yet again we had no choice.

36. Fortunately, we were able to access assistance for moving costs and necessary disabled adaptations from Caxton, with no problems and this assistance was much appreciated, as we could not have made the move without it. The only uncomfortable part was having to explain to the Solicitor and Estate Agent that they would have to wait for their monies as they were being paid by the Fund. No one made us feel small but we still felt like charity cases literally.
37. Prior to the move, I realised that my own physical condition was in such a state that I would struggle to manage to have the strength and energy to be able to fully participate; bearing in mind I would be unassisted. With this in mind having had a general assessment from a local health practitioner who was prepared to provide some remedial treatments in the home, I decided to approach Caxton in my own right to see if they could assist with the costs. They declined so I paid for therapy from my own DLA, and continue to do so to date. I do not regard this intervention as an indulgence, but a necessity in order to be able to function, as my conditions have in no way improved with age. I attach a copy of their letter at exhibit **'WITN3660003'**.
38. In 2016 my husband was offered a 24 week course of DAAV therapy as his clinical diagnosis for treatment eligibility was Compensated Cirrhosis, although he was never seen by a liver consultant. He embarked upon this with a renewal of the side effects experienced previously and which never really left, but this time the course was successful. He still has to attend his regular clinic at four month intervals, which is always an ordeal he rings for his results a few days later rather than having to wait and then there is the

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anxious interval until the next occasion, as things could still go wrong and this will continue for life.

39. Prior to beginning AV therapy my husband made some enquiries about it with the Haemophilia Society who were helpful, but who also advised him to claim Skipton Stage 2 payment, which he duly did, unsuccessfully. The resulting fiasco is detailed in his own witness statement – it seems to me that their system is deliberately set up to exclude as many sufferers as possible. I find it hard to accept that liver damage inflicted over decades is viewed with such indifference and lack of concern and I exhibit at **'WITN3660004'** copies of their accounts for 2016 which hold an interesting view of the matter.
40. There was also at this time a DoH sponsored consultation regarding the proposed SCM in which we participated. I also, out of interest contacted various bodies to ascertain their positions and I exhibit their replies at **'WITN3660005'**.
41. In 2017 my husband was invited to claim PIP as his DLA was due to end. The events which followed are chronicled in his own witness statement, suffice to say he was initially denied the high rate mobility portion he had been in receipt of for 45 years – thankfully we did not have a motability car to lose and over the years had deliberately avoided having one for this very reason, and the care portion remained as standard. After much turmoil it was reinstated, but I resented the upheaval and effort it caused.
42. In October of the same year when the NHSBSA came into being, my husband was assessed and received a welcome income top-up, for how long is unknown.
43. In 2018 my husband learnt via the Haemophilia Society that those receiving PIP who had haemarthropathy could apply to have their award re-evaluated with the provision of paperwork and evidence. Having had his condition from 8 years of age his reapplication was accepted and he was awarded a higher rate of care with no need for renewal for 10 years, a relief to us both.

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44. Also in this year my husband decided reluctantly (after the Skipton debacle) to apply for the new SCM payment. Having once again gathered sufficient evidence from those treating him, to our amazement he was on this occasion deemed "ill enough" and succeeded in his claim, although for how long this support will be available is again unknown to a degree.
45. On December 6<sup>th</sup> of this year, evidence of one of the after effects, from AV therapy ie poor concentration, that my husband experience, came to the fore when at about 7pm, he started to go upstairs on his perch stairlift. He then realised he had forgotten to bring something with him, set it off to go down again, and was so distracted that when he achieved what he thought was ground level stepped off, to realised belatedly that it had not fully reached the floor and fell fracturing his hip. Obviously being a severe haemophiliac he sustained immediate trauma/internal bleeding. I fell down the last few stairs trying to get to him, but apart from a foot injury I was ok. My first concern was whether he had a head trauma. This was not the case thankfully, but his own Centre was too full to admit him. They could only advise him to administer FVII, which was not possible due to his position and despite stating his condition for which he carries a Haemorrhagic State card, the ambulance didn't arrive for three hours. He was admitted to our local hospital at midnight, as my agoraphobia prevented me from accompanying him as he was alone, as was I for the first time in GRO-B years, not knowing how he would fare with surgery. Fortunately he took supplies of FVIII with him as the hospital had none. He remained there for five days until he was transferred to his Centre, where they replaced his hip and he received excellent care, although he had no visitors for the ten days he was there. We had to arrange a private courier to ferry some clothes and essentials to the ward. Thankfully we were able to keep in touch by phone and my natural health therapist was kind enough to get cash from the post office and post letters for me and Tesco's kept me supplied with food deliveries.
46. I have now unfortunately realised what it is like to have to managed without him, albeit for a brief spell of time and it has put into sharp focus what may potentially still be to come. As a result my anxiety and agoraphobia have

worsened and I doubt whether I will ever be the same again and it has made life for us both even more difficult and uncertain.

47. My husband is now recovering slowly although he has developed a post surgical hernia and has to be even more careful about what he does now. I am even more vigilant as he is more vulnerable now.

**Section 6. Treatment/care/support**

48. I wish to rely on my husband's witness statement in relation to this section.

**Section 7. Financial Assistance**

49. I wish to rely on my husband's witness statement in relation to this section.

**Section 8. Other Issues**

50. To conclude, I cannot help but feel that the contamination/infection incident has been the catalyst for everything that has ruined our lives physically, mentally, emotionally and financially. To combat this we seem to have developed emotionally stunted, nonplus, flatline personalities and a conspiracy theory mentality. We have an existence rather than a life. For years there has been a constant round of writing to MPs, listening to debates, filing in consultations and forms, begging and hoping for financial support, dreading GP and hospital visits and having no control over our destiny, as all decisions are coloured by the events that have transpired and my husband's liver condition. I am fully aware that for many others things have been and are much worse than our situation, although we do not yet know what is to come. If I could wish for anything it would be that we might have a chance to try and salvage something positive from what time we have left and achieve some kind of normality peace and security along with the justice and closure that is so vital for all concerned.

**Anonymity, disclosure and redaction**

51. I wish to apply for anonymity.

52. I do not want to give oral evidence to the Inquiry.

**Statement of Truth**

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

Signed..

GRO-B

Dated..

23/9/19