Witness Name: GRO-B
Statement No.: WITN0864001
Dated:

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 5th March 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B and my address is known to the Inquiry. I am the partner of GRO-B: P who is a Haemophiliac. I am recently retired, having worked as an NHS nurse for thirty-eight years.

2. I intend to speak about P's infection with the Hepatitis B Virus ("HBV"), the Hepatitis C Virus ("HCV"), the Human Immunodeficiency Virus ("HIV") and Variant Creutzfeldt-Jakob Disease ("vCJD"); which he contracted as a result of being given contaminated blood products to treat his severe Haemophilia A.

3. P and I have been together for almost a decade. P moved in with me just over five years ago, to my home in GRO-B P and his family are hyper vigilant about their anonymity and confidentiality in regards to P s condition. As a result, my normally open, transparent persona has transformed to enter their world of hidden secrets and unsaid words, and suffer their burden of injustice. It is not my place to tell their story openly and I have had to compromise myself to ensure that I do not cause them any worry or hurt. I am one of a tiny number of people that P s mum can talk to and only one of my friends knows about our circumstances.

Section 2. How Infected

4. P was born with a severe version of Haemophilia A. In his statement to the Inquiry (**WITN0869**) P has set out the blood products he received and the dates when he was diagnosed with each infection.

Section 3. Other Infections

5. P received a batch of Factor VIII, which was produced from a blood donor who had vCJD. P has set out how he became aware of this in his statement to the Inquiry.

6. This vCJD infection is of great concern to me because I worked in neurology wards and intensive care units for many years, and nursed two patients in the latter stages of vCJD. The nurse that told P that it is unlikely that he will contract vCJD in the future should not have said that to him, because it is not possible to know what future effects there may be. This absolutely terrifies me; vCJD is one of the most horrible illnesses that I have come across.

Section 4. Consent

7. From 10th October to 2nd November 1983, P was kept in isolation at GRO-B Hospital. The details of how this happened are set out in P's statement to the Inquiry.

8. P has told me that this was a scary and traumatic experience for him at such a young age. As a nurse, I can see no reason for such an extensive stay in isolation for such a minor injury. It is simply not acceptable to isolate a child for such a long time. This stay had a profound effect on the level of trust P has in nursing staff and medical professionals. We know that GRO-B Hospital had an infectious diseases department and P was diagnosed with HIV not long after his time there. This is very concerning and we wonder what may have taken place during the period that he was in GRO-B Hospital. P has given details of other occasions when he was kept in isolation in hospital in his statement to the Inquiry.

Section 5. Impact

9. Where do I start without writing a book? I will start by saying that the magnitude and scope of this abysmal tragedy ripples through families, tearing them apart. It destroys lives and plunges people into depression, financial hardship and a dark world of secrets and fear, isolating those it touches from their communities through fear and ignorance. Mentally and emotionally there is little fight left. Physically they are drained and war torn. Yet we keep going to the meetings and listening to yet another set of tragic tales, feeling their pain, but too exhausted to give proper support. We think: Will this person even be here at the next meeting? Or will there be another mother here grieving for a son? Or will it be, as usual, fewer people present, fewer people that have survived since we last met?

10. The impact this has had on the entire family is inexplicable. Often, as in P's case, there are siblings affected, each struggling to come to terms with this injustice in their own ways. The devastation something like this leaves in its wake goes on for years and years in so many people's lives. Some cannot cope with it at all and I believe the injustice and lack of

accountability has contributed to this. Since meeting my partner, my whole perspective on life, justice, politicians and fairness has totally changed. I see some politicians on the news or in the media and I feel physically sick at seeing at their smiling faces, knowing what they have done.

11. The mental and physical effects of being infected with HBV, HCV, HIV are immense. There are also other factors such as social, psychological and financial effects, which are far reaching and affect every part of every day of P's life and now we are together, both our lives.

12. It is very important to remember that people with haemophilia are already greatly disadvantaged from a health and wellbeing perspective. For example, P needs to have two or more intravenous infusions every week. This means undertaking full intravenous access to receive an infusion of factor. This is increasingly hard to deal with as time goes by, because of the difficulties with intravenous access, caused by failing veins and a reduced ability to manage the process due to limb restrictions from bleeds. There are also psychological issues and his overwhelming fatigue due to the HIV and HCV infections. Haemophiliacs suffer immense crippling pain when bleeds occur and subsequently are left with debilitating symptoms such as; immobility, joint stiffness and swelling. All this places them in an already vulnerable category without having to deal with the additional devastation of being given some of the most feared infections that exist to date.

13. Before being told of his multiple infections, P was a cheeky, lively, outgoing boy, with lots of friends and a good relationship with his brother. P's brother is also a haemophiliac and they were both told of their multiple infections in 1992, just as P started college. P's world fell apart. His brother was two years older; but he locked himself in his room for days and after that was a totally different person. He was angry, unapproachable and in total denial. He was not able or willing to discuss the infections with anyone, even his mum. This remains the case to this day. P's family was torn apart and as the younger sibling he had to try

and make sense of the turmoil within his home and his family, as well as cope with losing his relationship with his friend, his big brother.

14. To try and protect their children, P's parents adopted a veil of secrecy, but this led to P feeling scared, lost and very alone. Many friends who he used to see at the Haemophilia fund raising group that he attended with his parents stopped going after they found out about the infections. Nobody wanted to be seen as having HIV or HCV and nobody wanted to associate with those that did have the infections in case they became infected.

15. With all his self-confidence gone and what seemed like a death sentence hanging over him, P's whole demeanour changed. His very outgoing nature and sense of fun disappeared and he became quiet and introverted. P stopped going out, he lost his confidence and became lost and very lonely. He lost many friends and no longer socialised. The media campaigns with tombstones indicating that if you caught HIV you would die, compounded P's fear and anxiety and left him grieving for the life that had been so cruelly taken away from him.

16. At the time P's parents told him about his infection, he was around the age that boys would ordinarily begin getting interested in girls and relationships. P felt that he could never have a girlfriend, never have a family or have children of his own. There were so many obstacles and so much misinformation about being with a partner with HIV at the time. People believed they could contract it through kissing someone or even through drinking out of the same cup as someone with HIV, so in his teenage years and his early twenties, relationships seemed like an impossible dream.

17. P and his family knew many others in the same situation as him and they were dying, one after another. This meant you had to live for the day, as there was no future. P decided to focus on his health in every way possible. This meant: exercise, diets, fresh fruit and vegetables, no

processed foods, no sauces or additives, vitamin supplements, whole grain bread and no alcohol. This was his lifestyle from an early age and he remains the same today. However, for financial reasons, he has at times struggled to maintain that standard of diet. In his twenties and thirties, his assistance payments were so poor that he barely had enough money for tins of tuna and pasta, never mind fresh produce.

18. Since we met over a decade ago, I have seen how exhausting life is for P. He often has to take naps at home or stop driving to sleep. He only works two days a week now, one at the beginning and one at the end of the week so that he has time to recover. He feels that, without working, he would not be able to have holidays and would not be able to afford a decent standard of living. When he gets home from work, I take him a drink up, he eats his tea on the bed and then falls asleep. Sometimes it is the next morning before he wakes up. I sleep in the other room to not disturb him. On a non-work day, he often falls asleep on the sofa. I will go to get ready for bed and he will say that he will come up, and then go quiet. I know that he is asleep so I leave him to rest. If we sit down to watch TV, it is rare that we reach the end of an hour-long episode of anything and I can't remember the last time that he saw the end of a film. If I want him to help in the garden or go shopping or anything like that, I book it in advance so that we can do it when he's first awake, before he gets tired. He spends many hours each day resting on our bed.

19. Work is hard, only P's immediate boss knows of his plight. I worked in the same organisation and we were paranoid that people would discover his illnesses because of the impact it would have on our relationships with colleagues. Nurses should have a better understanding of HIV and Hepatitis, but they do not and I can vouch for that personally. P is also aware of this as he works in admin for infection prevention and control. The ignorance that employees demonstrate through their questions and comments is quite shocking at times. As a result of this, I have never told my work colleagues about P's infections, even those who are also friends. My status as a nurse could have been called into question solely

through association, and that would have been a nightmare. I retired last year because I could not stand the secrecy and listening to people's ignorance. I was able to retire at fifty-five years old without penalties. Financially, this was not the best situation but it took the strain off mentally.

20. To this day, we sit in hospital waiting rooms for hour after hour, test after test, seen by many different clinical teams. He has had many more blood tests than he would need had he not been infected, which is worrying as his veins are precious because he needs them to be able to take his factor. Veins don't last forever and P hates blood tests. He goes clammy and sweaty and gets snappy and fidgety. Many nurses have commented on how the colour drains from his pale cheeks. He goes grey and it takes a good half an hour afterwards to settle down again. His t-shirts get wet with sweat and he just wants to go home as soon as possible. If they start fiddling or moving the needle about to try and get access to his veins, I stop them.

21. I am, in many ways, his advocate. I see what he goes through. I sit for hours in clinics. We use holiday days so that nobody at work asks why he needs so many days off for hospital appointments. When P is having his bloods, I often hear people make comments like: "You'd think you would be used to it by now" and I want to shout at them. I want to say: "You do it every couple of days, when it's sore from last time, or you don't feel well, or your arms are stiff from a bleed, or you've just had an operation". They should see if they get used to it. It breaks my heart seeing him go through it, but I hide my hurt and my tears and make a joke so as not to upset him even more. I chivvy him along and make sure he's warm, as there is more chance of finding a vein when he isn't cold. I intervene to make things better in any possible way I can.

22. I am so very angry at the institution that I gave thirty-eight years of my life to as a nurse. The NHS motto is "to do no harm". I always trusted that the NHS would take care of those they treat, especially the vulnerable and

little children. They have a duty of care, but they have let P down in such an avoidable and unjust manner.

23. The intimate details of our relationship are hard for me to write, knowing that a total stranger will read it, someone who I do not know and who does not know me. Before we started our relationship, P was very open and honest regarding his health problems. He told me everything before making moves to have a relationship. I did not fully understand the enormity of the problem for a few months. I didn't understand how it affects everything, everyday.

24. I hate condoms; I find them uncomfortable because of scaring from a previous medical intervention. I would prefer to not use them, but unfortunately that is not an option in our relationship. Shortly after starting the physical side of our relationship, a condom we were using split. This meant we had to take a trip to A&E in Leeds. We could not go to our local hospital, as we both work there and nobody knows about P s infections. It was late on a Saturday night and full of drunken people. We had to sit and wait our turn. I had to start a three-month course of (PEP Post Exposure Prophylaxis). I was given tablets and had follow up appointments and blood tests. This meant more hospital visits, on top of P s, but it was reassuring to be safe from infection. I had not anticipated how bad the side effects of the tablets would be. It was like all day morning sickness, terrible diarrhoea and an awful taste in my mouth. They kept saying the symptoms would get better as I got used to the PEP but they didn't. I had to carry on taking them twice a day, knowing each time that I would feel horrible.

25. By the end of the treatment, I was clear and I had not contracted HIV or HCV. I felt for P He was so apologetic and understanding, but he felt such guilt for something that was not his fault. It gave me an insight into how his medication makes him feel. It helped me walk in his shoes and understand things like the rush back to the house to use the loo and why

he needs food before his tablets. It was not pleasant and I felt angry with those who had made us go through this.

26. The thing I find hardest about our relationship is to do with kissing, and this makes me very upset. P is my love, my soul mate and the bravest, most caring and considerate man that I have ever met. I love his kisses; they join us together in a special way. I still remember our first kiss clearly and with affection. However, it has probably been three months since we last had a proper kiss, other than a tiny lip peck. P has had recurrent tooth problems and has a temporary solution in place. I have had bleeding gums and inflammation. Also, at the same time, P or myself have had bitten cheeks, tongues or mouth ulcers. All this has meant no proper passionate, full-on kissing. Normally these oral problems wouldn't matter if P didn't have the infections, but he won't risk my safety and we have to be sensible. It is a constant reminder that we can't be like others, that these horrible viruses are ruining yet another part of our lives.

27. There has never been a question of us trying for children. P doesn't have the capacity to find out whether it would be possible because he ruled it out as an option many years ago. I am older than P and even though we have discussed having children, we felt there was enough to deal with emotionally as things are.

28. Colds and other infections are scary for P and I go to all possible lengths to avoid friends, colleagues and every day acquaintances who have obvious cold symptoms. I carry gel hand wash everywhere. If we go away we take antibacterial wipes to clean everything. I've cancelled get-togethers with friends because P doesn't like to go where there are large groups of people. Much of that is a confidence thing, but it is also to avoid colds. My family tell me if they've got a bug, they will say "You won't want to come because so and so has a cold." They don't understand why, they just think I'm being fussy. It's hard not sharing, because by nature I am so open and honest. I don't lie to them, I hate lies, but I skirt around things and word things carefully. It is very hard.

29. P has had pneumonia in the past and I looked after him. He gets a bad chest when he picks up colds and viruses. He gets very scared when his chest starts up as he has struggled to breathe in the past. This is probably due to the scaring on his lungs from previous infections. When this happens, we make sure he gets to the GP straight away for stronger antibiotics. He has the flu and pneumonia vaccines every year.

30. There is no way I would consider going to unusual places, which I would have done before I met P We play it safe by visiting places where there are good hospitals and we plan our breaks around rest and relaxation. On our last holiday we only left the hotel for a couple of hours once, to go to the local town. P was very worn out and I don't want to go to places alone. Holiday insurance prices are about £100 more than I used to pay. I believe these survivors should be given free cover. Some countries won't allow P to visit due to his infections. It is only recently that America would let him in, which is ironic considering the blood that infected him originated there.

31. One time we set off to Northumberland for a few days break and two hours into the journey we realised we had forgotten P's antiviral tablets. We rang St James's Hospital to see if they could send a script though to where we were heading. We were advised to divert to the nearest large hospital sexual health clinic where we could be prescribed the tablets. However, there was no guarantee that we could get them. There was no way he could miss the tablets and after weighing up the information we decided it would be best to drive back home to get them. I know it was our fault for forgetting them, but he shouldn't need the tablets because he shouldn't have the infection, so when things like this happen it is very hurtful, upsetting and makes me frustrated and angry.

32. P's education was compromised by all the additional hospital visits, ill health, a lack of support and missed schooling. There have been many times when P has had to stay in jobs where he was bullied, ostracised,

targeted or even victimised when people found out about his illnesses. Once he left an employer for another job, only for someone from his previous office to start there and tell everyone about his predicament. Finding jobs has been hard, confidence is a big reason for that, plus he also has to explain his health status to a total stranger. This has contributed to his depression and anxiety and made him introverted and quiet. This does not lend itself well to applying for promotion or putting himself forward for opportunities.

33. As a result of his infections and his difficulties with employment, P s financial position has been poor since we got together. He has had long periods of low or no income over the years and has re-mortgaged his flat twice to make ends meet. I have always worked and have been in a good place financially. When I asked P to move in with me the money he got from the Macfarlane Trust's monthly payments was cut by about £2,000 a year, which to him was massive. This meant he was much more reliant on my finances than before he moved in with me. Now I am retired I do not have anything like the income I did previously and with P working only two days a week, things are more difficult.

34. The other consideration is that, as P and others like him did not think they would be alive, any money they had was spent in a timely manner. There is no point paying a mortgage off if you won't need the flat. This has meant no savings and no emergency money. P 's car is old and has already been in the garage four times this year. He has no savings and, in his current job, his two days at work are too much for him. Overall, financially he is not in a good position.

Section 6. Treatment/Care/Support

35. The treatment and support that P received for his HCV and HIV is set out in his statement to the Inquiry.

Section 7. Financial Assistance

36 P found out that there was some financial assistance available when he was first told that he had been infected. I would expect that people in his position would receive a significant enough sum to ensure, at the very least, a quality of life equivalent to someone on the minimum wage. Yet despite all the major life threatening diseases he had been given, P received an ex gratia payment of only £20,000. This was unbelievably hard for him to deal with.

37 P found out, nearly twenty years later, that another £20,000 had been given to GRO-D, who had kept it from him. P and I were together when he discovered this at one of the meetings we went to. He was devastated and angry. The trust should have made sure that the money went to those infected directly or was held in a fund until they reached eighteen. So in total, up until the age of thirty, P received one lump sum of £20,000. I find this offensive, laughable, disgusting, and abhorrent. It is just another addition to the long list of injustices he has suffered.

38. In our time together, we have twice completed very lengthy forms to try to get some funds for P from the MacFarlane Trust. The trust had a few million pounds in reserve and was trying to decide how it should be spent. We went to meetings, we filled in their lengthy forms, but we received no feedback and no money. During this time, we went to a weekend event that the MacFarlane Trust had organised and was paying for. It was the last event of its kind, as many people who had previously attended these events had since died. On the tables at the meal were bottles and bottles of wine. I was furious with them for putting all the bottles of wine out when all of the sufferers have liver problems. It was just totally inappropriate and demonstrated how out of touch the MacFarlane Trust was with the victims it was set up to support. Even more disgusting than that was, because hardly any of the wine was drunk, they went round giving it away to people in the hotel who had nothing to do with our meeting group! Furthermore, one of the ladies, who I think was called GRO-D, excitedly announced to us that the fund had paid for her to do her social work

degree. Now all that money is gone. To make matters worse, the MacFarlane Trust sent us a letter saying the remainder of the money was handed over to the Terrance Higgins Trust. I would like to know who decided that. Why didn't they just give it to the survivors, who it was intended for? This was another vile injustice.

39. In 2004, P also received a Stage 1 payment of £20,000 for his HCV infection from the Skipton Fund. The remainder of what he received has been in the form of regular payments, which he has set out in his statement to the Inquiry. I know that there have been times when the amount was so minimal that P didn't have enough to live on. I was also very annoyed that, when P moved in with me, his discretionary payments dropped considerably. Am I the one who has to pay for what the politicians and NHS have done to him? I was beyond furious and I didn't want to send my information in. But I had no choice and now that I have retired his payments have increased again. Unfortunately, the same income questionnaire and rules are still in place with the successor to the Macfarlane Trust – the England Infected Blood Support Scheme.

40. None of the financial assistance has been enough to give P a reasonable standard of living without support from others. Other countries have properly compensated those infected, enabling them to not have to worry about money. In contrast, in England, those infected are required to fill out pages and pages of forms every year, and rely on others to survive. This is a disgrace and a damning indictment of successive governments.

Section 8. Other Issues

41. I am a caring person by nature, and as someone who has worked as a nurse for my entire life, I am not able to believe that the NHS and politicians have done this to so many thousands of people, without being morally, legally, publically and financially held to account. I have met many survivors and community members who sadly are no longer with us. I have sat next to mothers who have lost sons to these terrible diseases and have

felt emotions I never knew existed. As I write this, I think of the patients with vCJD that I nursed in the Neurological Unit many years ago. I worry about my brave and wonderful partner who on a daily basis battles with the emotional and physical trauma that has underpinned his life. So many have not made it this far and we feel that is what many governments have relied on to avoid providing answers. We were already a silent minority and each day there are fewer quiet voices to remind them of what was done.

42. I have not had a lifetime to get used to the injustice and the suffering of this courageous and forgotten community. When I met P, I became part of that world, and my journey to understanding the effect this has on every tiny part of P s life had begun. We often feel that the process of achieving justice has been drawn out for so long so that all the victims will die, as many thousands have already. There have been inquiries for many other disasters, and public cries for justice for the victims of those disasters. It feels like nobody calls out for justice for those infected with these terrible diseases.

43. I want to shout for the victims but I can't. I would be betraying the my partner's veil of anonymity, as well as that of the many community members I have met. Their first words before they decide to share their email address, phone number or name is: "You won't mention anything though will you, nobody knows."

44. We had hoped that the litigation that P was involved in would conclude with justice for the sufferers and their families. We hoped that once it was over, P would have peace, a good standard of living and would no longer need to worry about the illness or prejudice affecting him. Nothing could be further from the truth, and the outcome of the litigation has led to such grief and anger that it is impossible to understand by those who are not affected. The pharmaceutical companies made P and the other claimants sign a waiver so that no further claims could be made. This is so wrong because they were not in a position to reject the companies' offer.

After eight years of stressful litigation, using up valuable time, I see the settlement and waiver as a form of blackmail. It was another injustice. They had gone through years of stress and preparation, and it was all for nothing.

45. P and everyone infected has a shortened life expectancy and we have to live with that on a daily basis. Not a day goes by without constant reminders of their illnesses and struggles. A deep feeling of injustice clouds every moment of our lives. How is it that in Britain, where the NHS has a duty of care to patients, there has not been a settlement that gives back a little of what has been taken? It is incredulous. People's lives and families have been ripped apart, ruined and broken. People have died while others watch on knowing that it may be them next. Some people no longer go to their friends' funerals, as it is too painful a reminder of their own infections and their own mortality. Someone needs to do something and they need to do it soon, inquiries take a long time and those that are left of the contaminated blood community do not have that time.

46. There have been some great advocates for these survivors, who have a detailed understanding of the issues, such as Lord Archer and Lord Morris, who are now gone. Our faith that our overwhelming need for justice will be satiated is very low. Our trust in external organisations is destroyed. We have been let down by: the politicians, specifically the former Health Secretary Kenneth Clarke and the former Prime Minister John Major; the lawyers; the pharmaceutical firms; senior NHS staff; the financial organisations that are meant to offer support, such as the MacFarlane Trust; and previous attempts at providing justice, such as the Penrose Inquiry. To make matters worse, now the Haemophilia Society have led us down a distressing path with their recommendation of Malcomson Law solicitors and the subsequent confusion that ensued.

47. The Archer Inquiry did not get to the bottom of the facts; it did not establish what members of the government knew, what the drug companies knew or what information was passed between the two. The Penrose Inquiry

dashed everyone's hopes for justice and plunged P into a deeper depression. I was very angry and it has taken a long time to bounce back from the findings. This inquiry is the last hope that we have of getting the truth exposed and of showing this vulnerable group that they matter, that they deserve a decent quality of life, that they are not just being left to fall one by one and that they do have a voice that is being heard. This means financial security as well as peace and an exposure of the truth.

48. Finally, I want to say that P and I have both found this process very, very stressful. We have argued and snapped and been generally impatient with each other whilst writing and discussing our statements. This is out of character for our very amiable and loving relationship. It demonstrates the immense pressure that we experience each time we have to revisit the tragedies that we have suffered. I feel a great sense of relief knowing I am writing the last paragraph and just pray that in the end it will be worth it for this inquiry is the very last hope for justice.

Statement of Truth

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

Signed ________ GRO-B Dated 27/8/2019